Perspectives on disclosure of HIV status to others among 12-19year old HIV-infected adolescents attending an HIV care clinic at a tertiary hospital in Harare, Zimbabwe: a qualitative study

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DECLARATION

I, *Rabia Khan,* hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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ABSTRACT

Introduction: The worldwide commitment to increasing services and access to antiretroviral therapy have resulted in a decline in HIV related mortality. As a result, the focus of HIV care is shifting towards improving the psychological health and quality of life. HIV infected adolescents are a group with unique psychosocial challenges. Given that HIV self disclosure has been recognized as an important challenge affecting their physical as well psychological health it warrants further exploration.

Methods: A qualitative study was conducted during September to November 2014 among adolescents (12-19years) attending the HIV care clinic at a tertiary hospital in Harare. Twenty adolescents who were vertically infected with HIV were recruited using purposive sampling techniques to achieve maximum variability in age and sex. In depth interviews were conducted to determine the views of adolescents regarding when, whom and how to self disclose. All the interviews were transcribed verbatim. Data was analyzed using the framework approach.

Results: Adolescents identified stigma and discrimination from peers as well as lack of HIV knowledge as important barriers to status disclosure and suggested societal resources like support groups and media to assist them in the disclosure process.

Conclusion: HIV status disclosure to others is a challenging task for adolescents and it can be affected by personal as well as social factors. In order to deal with disclosure dilemmas, we have to work with adolescents keeping all these factors in mind to assist them in decision making, there by facilitating healthy supportive relationships and contributing to the wellbeing of HIV-positive adolescents.

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LIST OF ABBREVIATIONS

AIDS Acquired Immune Deficiency Syndrome

ARV Anti Retro Viral

ART Anti Retro-Viral Therapy

DALY Disability Adjusted Life Years

HAART Highly Affective Anti-Retroviral Therapy

HIV Human Immune Deficiency Virus

LAMIC Low and Middle Income Countries

PMTCT Prevention of Mother To Child Transmission

UNAIDS Joint United Nations Programme on HIV/AIDS

WHO World Health Organization

CHAPTER 1: INTRODUCTION

The worldwide commitment to increasing services and access to antiretroviral therapy has significantly improved the survival of people living with Human Immunodeficiency Virus (HIV). From 2005-2012 HIV related death rate has reduced globally by 30% (UNAIDS, 2013). However HIV/Acquired Immune Deficiency State (AIDS) remained one of the significant causes of morbidity. According to 2010 Global Burden of disease Study, HIV/AIDS remained the 5th leading cause of disability adjusted life years (DALY) globally and top leading cause of DALY in Southern Sub-Saharan Africa (Ortblad, Lozano, & Murray, 2013).

During the last decade, HIV infected adolescents have emerged as an important group for a number of reasons. First, there is a high burden of adolescents living with HIV. In 2012, according to UNAIDS estimates there were globally 5.4 million adolescents and young adults between the ages of 10-24 years (UNAIDS, 2012b). The reasons for this increased burden include the high risk of acquisition of new infections among young adults (Di Risio, Ballantyne, Read, & Bendayan, 2011), improved survival of vertically infected children (Cardoso et al., 2012) and children acquiring new infection through mother to child transmission. Despite improvements in prevention of mother to child transmission (PMTCT), 9300 children were born with HIV in 2012 in Zimbabwe (UNAIDS, 2012a). Second, there are high mortality rates among adolescents living with HIV. The UNAIDS 2012 Global Report expressed concerns over the 50% increase in mortality rate from 2005 to 2012 among adolescents (UNAIDS, 2013).Finally, HIV/AIDS is characterized by the challenges of any chronic disease such as fluctuating physical and psychological health, chronic use of drugs, stigma and difficult social situations (Siegel & Lekas, 2002) which are only exacerbated during the adolescent period.

Although most studies on HIV status disclosure and adolescents focus on whether, how and when to disclose HIV status to adolescents (Gerson et al., 2001; Kidia et al., 2014), currently the emphasis has shifted towards exploring the disclosure practices of adolescents to others (Siu et al., 2012; Mburu et al., 2014).). This shift in research focus is not surprising given that HIV self disclosure has been found to be associated with several advantages such as improved drug adherence (Stirratt et al., 2006) , social support (Shacham et al., 2012), and a better physical

(Calabrese et al., 2012) as well as psychological health (Vyavaharkar et al., 2011).The importance of adolescents disclosing to others have recently been acknowledged in a World Health Organization (WHO) policy brief providing recommendations on how to support adolescents in disclosure to others. In this policy brief, it is recommended that "adolescents should be empowered and supported to decide if, when, how and whom to disclose"(World Health Organization, 2013). However, how to support adolescents in the difficult process of disclosure was identified as a research gap in low and middle income countries (LAMIC), including Zimbabwe.

There are few studies conducted in the developed world that have explored the self-disclosure of HIV infected adolescents (Di Risio et al, 2011; Fair & Albright, 2012; Hogwood, Campbell, & Butler, 2013).However there is a paucity of data on self-disclosure among HIV infected adolescents in Sub-Saharan Africa. A study conducted in Zambia and another in Uganda have explored barriers, facilitators, outcomes and disclosure strategies among HIV infected adolescents and young adults (Mburu et al., 2014;Siu, Bakeera-Kitaka, Kennedy, Dhabangi, & Kambugu, 2012).However, at the present time there are no such studies conducted in Zimbabwe. Therefore, the present study attempts to address the issue of self-disclosure among HIV infected adolescents in Zimbabwe.

1.2: Aim

To explore the perspectives on HIV status disclosure to others in 12-19 yrs old HIV infected adolescents attending an HIV care clinic at a tertiary care hospital in Harare, Zimbabwe.

1.3: Objectives

1. To explore the views of HIV infected adolescents on HIV status disclosure to others.
2. To describe the disclosure strategies of adolescents who have disclosed and anticipated strategies for those who have not.
3. To determine the perceived barriers and facilitators of HIV status disclosure.
4. To explore the experiences of HIV infected adolescents with support group and healthcare providers during the disclosure process.

1.4:Outline of the dissertation

In Chapter 2, I will present the literature review which provides a background to the study. In Chapter 3 the methodology of the study will be described. In Chapter 4, results of the study will be presented and in Chapter 5, the findings of the study will be discussed and will be compared against both international and regional literature, in addition to making recommendations for policy, practise and research.

CHAPTER 2: LITERATURE REVIEW

2.1:Introduction

The literature review will commence by looking at the importance of the adolescent period in general, followed by the importance of adolescents as a group in the HIV epidemic. This will lead to a discussion of the issues faced by HIV infected adolescents in this era of Highly Affective Anti-Retroviral Therapy (HAART) and improved survival. Then, available research investigating HIV status disclosure to children and adolescents will be discussed. Finally, I will focus on HIV self-disclosure and the challenges and dilemmas faced by HIV infected adolescents worldwide as well as in Africa providing the background and rational for the aim of the present study.

2.1.1: Importance of the adolescent period

Adolescence is a difficult time of life associated with a major transition from childhood to adolescence. Reasonable risk taking behaviour is considered normal in adolescence (Saddock & Saddock, 2007) and helps them to develop a sense of mastery and confidence in making new relationships, and navigating social situations and sports activities. However, high risk behaviours can lead to negative consequences, including substance misuse, risky sexual behaviour, driving under the influence of drugs and risky sport activities (Saddock & Saddock, 2007).Adolescents also face unique psychosocial challenges. This is a time when they develop sense of self, make their career choices and experience romantic relationships for the first time. These challenges can be further compounded by the added burden of a chronic stigmatizing and potentially transmittable disease like HIV.

2.1.2: Importance of adolescents in HIV epidemic

When the first case of HIV/AIDS was diagnosed in the 1980s, no one thought that vertically infected HIV positive children would ever survive into adolescence and adulthood. In 2013, 1.2 million adolescents (10-19yrs) were living with HIV world-wide and 64% of these adolescents were living in Eastern and Southern Africa (WHO, 2013) and this number is growing. There are several reasons for the increase in the number of HIV infected adolescents. Firstly with the advent and expansion of anti-retroviral therapy programs, survival of HIV infected children has

improved (Cardoso et al., 2012) and increasing numbers of vertically infected HIV positive children are surviving into adolescence and adulthood (Van Dijk et al., 2011). Second, the number of HIV infected adolescents continues to increase due to continued mother to child transmission. This is despite improvements in prevention from mother to child transmission (PMTCT) programs (UNAIDS, 2014). Finally, acquisition of HIV by sexual transmission is on the rise. According to the WHO it is estimated that adolescents contributed to 1/7 of all new HIV infections (WHO, 2013). In 2013, 250,000 new infections occurred in adolescents between 15 and 19 years of age (UNICEF, 2013). Another study focuses our attention on the gender difference in the spread of HIV epidemic where females (15-19yrs) are at 6 times higher risk of getting HIV infection than males in Sub-Saharan Africa (Glynn et al., 2001). This finding has the potential to increase vertical transmission of infection and to further increase the number of HIV infected children and adolescents.

2.1.3: Challenges faced by HIV infected adolescents

As the HIV epidemic is maturing and HIV/AIDS associated mortality rates are declining, the world is giving more attention to issues linked with quality of life. According to a review article discussing the challenges faced by vertically infected adolescents, the important concerns identified included psychosocial issues, adherence to drugs, and reproductive health (Lowenthal et al., 2014). HIV status disclosure has been shown to be associated with physical and psychological health, medication adherence, as well as reproductive health. Reproductive health specifically will be discussed with the importance of status disclosure in sections 2.1.4 and 2.2.5.

2.1.4:HIV status disclosure to adolescents

Disclosure of HIV status among adolescents has two aspects. The first aspect deals with disclosure to children and adolescents regarding their HIV status, and the second aspect is linked to children and adolescents disclosing their status to others. Many researchers have investigated HIV status disclosure to children. According to the findings of a review article, in LAMIC rates of disclosure were lower (median rate of disclosure 20%) and mean age of HIV status disclosure (median age 8.9 yrs) was higher compared to high income countries (Pinzón-Iregui, Beck-Sagué, & Malow, 2013). Improved drug adherence (Cluver et al., 2015;Vreeman, Gramelspacher, Gisore, Scanlon, & Nyandiko, 2013) and health benefits (Krauss, Letteney, Baets, Baggaley, &

Okero, 2013) have been consistently found to be associated with disclosure. Yet, many caregivers and healthcare providers are reluctant to disclose the child's status to the child (Thoth, Tucker, Leahy, & Stewart, 2014). The most commonly reported barriers to status disclosure described in the literature are the risk of spread of information by children, fear of stigma (Vreeman et al., 2013) and the fear of adverse psychological effects on children (Pinzón-Iregui, Beck-Sagué, & Malow, 2013).

A systematic review conducted on the psychological adverse effects and disclosure found mixed results (Vreeman et al., 2013). These findings may depend on when the psychological maladjustment (Internalizing and externalizing symptoms) was measured. Another interesting finding reported by qualitative studies that investigated this issue is the concept of change in emotions over time leading to acceptance (Petersen et al; Mburu et al., 2014). Further studies have explored the role of caregivers and peer groups in psychological adjustment after disclosure(Menon et al., 2007; Kidia et al., 2014).

One Zambian study has emphasized the role of relatives facilitating the process of disclosure by talking to adolescents about HIV and showing their acceptance of HIV as a disease prior to full disclosure (Mburu et al., 2014). However, a qualitative study done in Zimbabwe, concluded that adolescents prefer initial disclosure to be done at health settings and peer support was found to assist in psychological adjustment (Kidia et al., 2014). Another study conducted in South Africa highlights the importance of developmentally appropriate disclosure and emphasized that disclosure is a process and not a "one point event" (Lesch et al., 2007). As a result of these studies' findings the WHO has published guidelines on how to support families and to guide health care providers in the disclosure process (WHO, 2011). Furthermore, qualitative research has shed light on the relationship between status disclosure to adolescents and self-disclosure to others, where negative experiences during status disclosure to adolescents adversely effected their decision to disclose to others (Fair & Albright, 2012).

2.2: HIV self disclosure to others

A structured review was conducted on all literature that has investigated the self disclosure of HIV-positive adolescents to others. The methods and findings are presented below.

2.2.1:Search Methods

An electronic database search of PubMed and EBSCO host was conducted to look for peer-reviewed articles between May to June 2015. The following search terms were used "status disclosure", "self-disclosure", disclosure AND HIV OR AIDS AND adolescents OR teenagers OR young adults OR youth. In the PubMed database, restrictions for language (English only) and species were made and in EBSCO host, the search was restricted to English language articles only.

2.2.2 :Inclusion/Exclusion Criteria

The following inclusion criteria were used:

1. Those studies where participants were either adolescents or young adults or youths.
2. Those studies where HIV status disclosure to others was explored including disclosure rates, disclosure strategies, disclosure patterns and facilitators and barriers of disclosure.
3. Both quantitative and qualitative studies on HIV status disclosure to others were included.

All studies, which were not in English were excluded.

2.2.3:Numbers of Studies Located and Data Extraction

Using the search methods as described above, 125 articles were located on PubMed. After the application of species and language restrictions, 99 articles remained on the list of searched articles. The titles of all these articles were assessed to ascertain the relevance. 36 articles were found to be potentially relevant. The abstracts of all these 36 articles were assessed and 15 were found relevant and full manuscripts were downloaded for these as shown in the PRISMA diagram in appendix VI. A number of themes regarding disclosure were addressed in these papers. I will begin by a general discussion about status disclosure to others, then I will present the evidence regarding the importance of self-disclosure, followed by disclosure dilemma and then barriers and facilitators of disclosure. Thereafter I will discuss some disclosure and non-disclosure strategies as described by HIV infected adolescents.

THEME	NO. OF STUDIES
1. If and when to disclose	6
2. Disclosure strategies	2
3. Barriers and facilitators of disclosure	11
4. Importance of disclosure	8
5. General views about support group	2
Total studies (including overlap)	15

2.2.4: Disclosure among adolescents

Disclosure of HIV status to others is a difficult decision. Qualitative studies have brought important insight into the challenges faced by vertically infected adolescents when explaining the tell tale signs of HIV in the form of parental demise, the need for taking medications and body changes like short stature, thin body and skin rashes (Hogwood et al., 2013). At the same time, children and adolescents want to be more in control of their decision to disclose to others (Siu, Bakeera-Kitaka, Kennedy, Dhabangi, & Kambugu, 2012). However in reality adults do influence their decision to disclose to others and un-necessary third party disclosure is common.

In the literature with adult participants, wide variations in disclosure rates to others were noted often linked with personal, inter-personal factors as well as the location where the study took place. These rates were noted in a number of studies including a review containing studies from high income countries as well as a systematic review conducted with women in Sub-Saharan Africa (Mayfield et al., 2008; Tam et al., 2015).

A review article showed similar variations in disclosure rates as well as associated factors among youths, however parental influence in decisions to self-disclose was identified as an important difference from adults (Thoth et al, 2014). In this review article, overall disclosure rates among youths ranged from 97% to as low as 52% in studies conducted in America and Thailand respectively (Rongkavilit et al., 2010; Lam, Naar-King, & Wright, 2007a). Moreover, these disclosure rates varied widely when considered different relationships. For example, disclosure rates of 22-65% to friends, 9-68% to romantic partners and 28-50% to teachers (Lee & Oberdorfer, 2009;Michaud et al., 2009;Wiener & Battles, 2006). On the other hand, few adolescents disclosed their status openly to the general public (Siu et al., 2012).Overall, many

studies have found low disclosure rates among young people, indicating the need to explore issues around HIV status disclosure in order to guide adolescents in the decision making process.

2.2.5: Importance of self disclosure

Most of the available literature on the importance of HIV self-disclosure is derived from cross sectional studies and therefore reveal associations rather than causality. Disclosure to others has been found to have personal as well as public health implications. On a personal level, cross sectional studies have shown that status disclosure is associated with safe sexual behaviour, social support (Shacham et al., 2012), improved drug adherence (Stirratt et al., 2006), as well as better physical (Calabrese et al., 2012) and psychological health (Vyavaharkar et al., 2011).Some of these personal factors in turn improve public mental health as according to a review article, improved adherence to antiretroviral drugs and reduced viral loads also reduce the risk of transmission of disease to others (Attia, Egger, Müller, Zwahlen, & Low, 2009). Finally, HIV self-disclosure has been found to improve public mental health by reducing the stigma associated with HIV(UNAIDS, 2000).

However, there are some contradictory findings in the literature. Some cross-sectional studies have linked disclosure to an increase in mental health problems (Roux et al., 2011;Lam et al., 2007; ;Khan, 2013)and less safe sexual behaviours (Rice, Batterham, & Rotheram-Borus, 2006). One cross-sectional study and importantly a systematic review, confirmed that HIV self disclosure was not always found to be associated with safe sexual practices (Geary et al., 1996; Sullivan., 2005).These contradictory findings stimulated further research into the possible explanation of these findings. In the case of unsafe sexual practices after self-disclosure, cross sectional data suggests that due to decreased viral loads resulting from the use of antiretroviral drugs, youths feel healthy and report that that using protection should be their partner's choice after disclosure (Rice et al., 2006). Similarly there is some evidence that disclosure beliefs determine the psychological outcome of status disclosure, where positive disclosure beliefs are associated with disclosure (Patel et al., 2012). This part of literature review emphasizes on the point that HIV self disclosure is a complex issues which involves a myriad of multiple factors. Therefore it is important to understand adolescent's thoughts and dilemmas on self-disclosure.

2.2.6: The disclosure dilemma

Qualitative research has brought important insights into the disclosure plans of adolescents, such as the issue of ambivalence regarding disclosure. Young adults as well as adolescents do not feel comfortable disclosing to others, especially friends and romantic partners (Mburu et al., 2014; Hogwood et al., 2013). In the available adult literature, this dilemma has been described and in African countries, the disclosure to family members was more common than to friends (Greeff et al., 2008). Moreover, multi-site case studies showed a significant time lapse of 5yrs or more before HIV self-disclosure (Hadjipateras et al, 2004). Therefore it is not surprising that some adolescents showed reluctance to disclose and described ways to evade the truth like lying about the purpose of their visit to the HIV care clinic and about the use of antiretroviral drugs (Mburu et al., 2014). However, most do agree that disclosure is "inevitable" and it will occur "when the time is right"(Hogwood et al., 2013). They mentioned times such as when they want to be intimate with a partner, get married (Di Risio et al., 2011), want to have children, when their friends will be more mature and understanding (Gillard & Roark, 2012;Hogwood et al., 2013) or when they will be less dependent on others (Siu et al., 2012).It is important to explore barriers and facilitators of status disclosure, so that well focused interventions to assist adolescents in the disclosure process can be developed.

2.2.7: Factors associated with HIV status disclosure

There are numerous factors that have been found to be associated with HIV status disclosure to others. These factors can be divided into personal, relationship and societal factors. These factors can act as both facilitators and barriers to status disclosure. I will discuss the factors according to these categories.

2.2.7.1: Barriers to status disclosure

The literature describes barriers to HIV status disclosure on personal, relationship and societal levels. I will discuss these, dealing with personal factors first. These personal factors were explored in both qualitative as well as quantitative research and include lack of communication skills and confidence to talk about disclosure, normalization and a desire to live a normal and carefree childhood without worrying about disclosure (Forsberg et al., 1996; Hogwood et al., 2013). Normalization has been studied extensively in the chronic disease model among children

as well as adults (Robinson, 1993;Protudjer, Kozyrskyj, Becker, & Marchessault, 2009). Normalization refers to the stage of acceptance of a disease. HIV infected youth from the developed world expressed their sentiments in a qualitative study, by saying that they look normal and can do anything so why do they have to disclose to others(Di Risio et al., 2011). Thus, although acceptance of the diagnosis may be seen as a positive event, this is still linked with non-disclosure for some adolescents. Similarly among adults, qualitative research linked non-disclosure with a wish to lead a normal life where people felt that HIV self-disclosure does not allow you to lead a normal life (Greeff et al., 2008).

The literature has described several barriers associated with significant others. These barriers were elicited in qualitative studies and include fear of rejection, fear of breach of confidentiality and the anticipated psychological impact on their relatives. Similar factors were described in a multi-site qualitative study conducted in Africa among adults (Greeff et al., 2008).The fear of rejection by peers and romantic partners has been noted to be an important perceived barrier to self-disclosure in qualitative as well as a mixed method study, fear of rejection is demonstrated by the following quote: "People might get scared and then you might be lonely for the rest of your life" (Chenneville et al., 2015;Hogwood et al., 2013;Fair & Albright, 2012;Mburu et al., 2014; Bakeera-Kitaka et al., 2008).The fear of breach of confidentiality was another frequently mentioned barrier to disclosure leading to secrecy and putting people in a "passive position" (Hogwood et al., 2013; Siu et al., 2012; Leonard et al., 2010). Concerns about an adverse psychological impact on their families also prevented disclosure as described in this quote: "if you tell your parents who least expect you to be infected, they can get shocked and they can die" (Siu et al., 2012a). Adolescents have also admitted that financial dependence on others and lack of available psychological assistance after status disclosure is another barrier to status disclosure (Siu et al., 2012;Forsberg et al., 1996) .

Finally, a number of societal factors appear to be important barriers inhibiting disclosure to others. Stigma and discrimination are considered to be among the most important barriers preventing disclosure among youths as elicited by the qualitative research (Siu et al., 2012; Hogwood et al., 2013; Bakeera-Kitaka et al., 2008; Di Risio et al., 2011). A systematic review including 17 studies from the developing world confirmed stigma and discrimination as a major barriers of HIV status disclosure among adults (Medley et al., 2004). HIV/AIDS related stigma

has been found to be worse than the stigma associated with other chronic illnesses due to its association with illicit drug use, sexual risk taking behaviours, marginalized groups like gay and lesbian men and women and commercial sex workers (Day, Ross, & Dolan, 2003). However, despite having no association with the above mentioned stigmatizing factors, vertically infected children and adolescents remained victims of stigma and discrimination in society (Bicego G & Rutstein S, 2003).

Different forms of HIV/AIDS related stigma have been described in the literature. This stigma can be in the form of "enacted stigma", "perceived stigma", "internalized stigma" and lastly "stigma by association". Enacted stigma or discrimination has been mentioned widely among adults as well in the few studies conducted among youth with HIV. Enacted stigma or discrimination is associated with "actual experience of acts of discrimination (Valle et al., 2015) and among children and adolescents include discriminatory behaviours like refusal of school admission for children, avoidance of physical contact like hugging or kissing, and by refusing to share utensils or the same toilet with them, or in rare instances threat of violence (Hogwood et al., 2013).

Perceived stigma occurs when people living with HIV anticipate negative reactions from others regarding their HIV status. This is manifested as fear of others' thoughts and actions when others either know or suspect someone to be HIV positive (Choi, 2014). Perceived stigma is manifested as avoidance to form close relationships with friends as well as romantic partners due to fear of rejection or spread of their secret information or at times even fear of talking in general about HIV(Hogwood et al., 2013). Self or internalized stigma is when HIV infected people accept the stigmatizing behaviour by others, blame themselves for their fate and accept the discriminatory behaviours of others (Herek et al., 1998).Internalized stigma is expressed as feeling guilty, worthless and ashamed of themselves due to having HIV(Simbayi, Kalichman, Strebel, & Mqeketo, 2007). Lastly, secondary stigma, or stigma by association is stigma experienced by family and health care workers due to their association with HIV infected patients (Herek et al., 1998). Children may be teased by others if they are known to be associated with HIV positive parents or siblings. This is manifested as calling their mothers' names as for example "prostitutes" and teasing them that will catch HIV from their parents by casual contacts or by people actively discriminating against them (Deacon & Stepheny, 2007) .

All these forms of stigma have been associated with non-disclosure. Perceived stigma has been found to be significantly associated with reasons for non-disclosure. These reasons for non-disclosure are fear of rejection, privacy, superficial relationships with others, inability to communicate the results and protecting others from the traumatic news. Internalized stigma leads to poor self concept as well as non-disclosure. As a result of stigma and non-disclosure, isolation, lack of social support and depression can result as the ultimate outcome (Simbayi et al., 2007).

2.2.7.2:Facilitators of status disclosure

There are several factors which potentially can assist adolescents in the disclosure process. These factors can be divided into personal factors, factors linked with significant others and societal factors. I will first describe facilitators on a personal level. These facilitators are linked to gender, sexual orientation, time period and circumstances of HIV status disclosure to them as well as some autonomous motivators. Disclosure and its association with gender and sexual orientation was explored in a cross-sectional study in Thailand and findings were as follows: Girls disclosed more often to their families while boys disclosed to their friends. Heterosexual men disclosed more often to their families as compared to homosexual men (Rongkavilit et al., 2010). Those who knew their HIV status for longer and had positive experiences during status disclosure to them, were more likely to disclose their HIV status to others as shown in a quantitative and qualitative study respectively (Batterham et al., 2005; Fair & Albright, 2012). For this study, I have used the term autonomous motivators as factors linked to a person's psychological gain, for example to give him hope or to gain closer relationship with others as well as an altruistic motive of helping others. These factors were highlighted in qualitative studies as follows: Adolescents admitted to developing a sense of hope by improved knowledge that HIV doesn't mean they can't have family or children (Di Risio et al., 2011). They also mentioned disclosure as a means of gaining a "close relationship" or a deeper understanding of their friends (Gillard & Roark, 2012). Some adolescents mentioned an altruistic motive, where they felt that their disclosure might facilitate others getting tested and seeking help before their health deteriorates. This motive seemed to be linked to adolescents developing a sense that "HIV isn't me" and thinking about HIV as a part of their lives (Di Risio et al., 2011;Gillard & Roark, 2012).

Facilitators linked with significant others include trustworthiness of others, knowing someone for longer periods of time and the nature of relationship (Fair & Albright, 2012;Di Risio et al.,

2011). Interestingly, the research suggests that disclosure patterns vary with different relationships and modes of acquisition of HIV as shown by cross-sectional studies in Africa as well as multi-site studies in high income countries as follows: Disclosure to family members was less in behaviourally infected youth as compared to adults (O'Brien et al., 2003). When they did disclose, more disclosed to the mothers then fathers (D'Angelo et al., 2001). On the other hand, most vertically infected adolescents agreed that disclosure to "family is unavoidable" and showed acceptance to disclose to family (Siu et al., 2012). Among family members, disclosure happened more often to those who they stay with. Youths who acquired HIV behaviourally disclosed to friends more often than vertically infected (Abramowitz et al.,2009). In the case of a sexual relationship, disclosure was found to be more common to the main partner and when the sero-status of the partner is known to be positive (Dempsey et al., 2012; Erku et al., 2012).

Societal factors have not been explored much in the literature. However stigma reduction could facilitate disclosure. Moreover the literature suggests that improved HIV education has been used to improve societal attitude and stigma towards people living with HIV. Media has been utilized in Malawi and Botswana to assist in stigma reduction which indirectly might facilitate status disclosure to others (O'Leary A, Kennedy M, & Galavotti C, 2007;Creel, Rimal, Makandawire, & Brown, 2011).

In adult literature, most of these factors are confirmed. Few additional findings in a multisite study in Africa include ethnicity affecting whom to disclose, where African disclosed more commonly to family members as compared to friends as in Western studies. Secondly, it was found that looking at disclosure as a mean to help others was a unique finding for African culture. Finally counselling, improved knowledge about HIV and advice from health professionals, were acknowledged as facilitators of HIV self disclosure (Greeff et al., 2008) .

2.2.8: Disclosure and non-disclosure strategies

A few qualitative studies have investigated disclosure, and non-disclosure strategies among youth. For example, in the US, young adults reported using strategies like avoiding relationships to hide their secrets or terminating relationships before intimacy; or going slowly to better understand the person before disclosure (Fair & Albright, 2012). Similarly in Canada, adolescents thought disclosure is possible in long term friendships (Di Risio et al., 2011). Most

of the above strategies refer to adolescents planning to disclose eventually if they can trust the other person with their confidential information.

In a qualitative study conducted in Uganda among young adults, disclosure strategies were explored. Adolescents who disclosed their status reported using both explicit and implicit strategies (Siu et al., 2012). In explicit strategies, young adults disclosed their status by telling others the name of the disease they are suffering from. In implicit ways status disclosure included strategies such as leaving their medicines or treatment cards in the open. Some young adults described a process of disclosure in which they initially started with joking or telling a story about HIV and judged the possible reactions. They tried these strategies to prepare them for the full disclosure later on. Some participants thought that it is better to take assistance from a third party like health care professionals. They thought that the health professionals were more experienced in conveying such information.

In summary, at the present time there are few studies conducted on self-disclosure in HIV infected adolescents in Africa. With a majority of the research focusing on reproductive health and sexual behaviours of youths (Birungi, Obare, Mugisha, Evelia, & Nyombi, 2009; Bakeera-Kitaka et al., 2008), only two studies have been identified in Africa that focused specifically on the disclosure process (Siu et al., 2012; Mburu et al., 2014). One of these studies was conducted in Uganda and the participants were HIV infected young adults(15-24 yrs). Disclosure patterns, barriers and facilitators as well as disclosure strategies were explored. However, the sample was not representative of all adolescents and they only included the youths who were on antiretroviral drugs (Siu et al., 2012). Those who were not receiving drugs can be a heterogeneous group, including those with less severe disease or those who are eligible but waiting to be commenced on anti-retroviral drugs (for example they are undergoing the blood tests or counselling before the commencement of antiretroviral drugs). Similarly, a Zambian study explored barriers, facilitators and outcomes of self -disclosure by adolescents (10-19 yrs old)(Mburu et al., 2014). Strengths of the Zambian study was data were collected from adolescents, their caregivers and health providers (triangulation).The Zambian study participants were receiving comprehensive HIV care including clinical services as well as many non-clinical services including “nutritional support, youth-led peer support, adherence and psychosocial counselling, home visits and other psychosocial counselling”. These comprehensive services are not widely available in Zimbabwe.

Moreover, at the present time there is no study conducted in Zimbabwe on self-disclosure among HIV infected adolescents, therefore there was a need to explore self-disclosure among HIV infected adolescents residing in Zimbabwe.

Additionally, the WHO has called for data regarding self-disclosure in order to translate WHO policy on disclosure among adolescents into strategic plans and guidelines. This is also in line with the WHO recommended self management model for chronic illnesses (World Health Organization, 2001). This model enables patients to take an informed and active role in managing their disease, and highlights the need to inform adolescents and support them in the decision making process. In the study conducted in Zambia described above, it was concluded that HIV infected adolescents value services which are "welcoming, empowering and provide tailored information" to their needs (Hodgson, Ross, Haamujompa, & Gitau-Mburu, 2012). Therefore, it is important to explore the views of adolescents living with HIV in Zimbabwe to assist them in the difficult process of disclosure and to inform future practice and policy. The present study attempts to address this gap.

CHAPTER 3: METHODS

3.1:Study Design

A qualitative study design using in-depth interviews was used. This study design helps to gain insight into people's perceptions and experiences by systematic interactions with the participants (Burns, Grove, & Gray, 2011). In depth interviews are considered a suitable style when exploring deep understanding of sensitive issues.

3.2:Settings

This study was conducted at the HIV care clinic at Harare central hospital. This hospital is one of the two largest tertiary care hospitals in Zimbabwe, as shown in the map in Appendix V. There are 600 HIV infected adolescents enrolled at this weekly clinic. The clinic is under the supervision of a senior Paediatrician. The nurses and counsellors do the routine interview. Those patients who pick up their drugs at the hospital usually get a prescription from a nurse practitioner. Review patients are seen by the doctors. Time to review the patients is decided on WHO clinical guidelines, which is based on the clinical state of the patient. There is no dedicated adolescent support group at this hospital. However the participants can attend the community support groups. There is a clinic policy which recommends that adolescents should have a full knowledge of their HIV status by the age of 12 years.

3.3: Study Population

A sample of 20 HIV infected adolescents between the ages of 12 and 19years were recruited from the HIV care clinic at Harare Central hospital from August to November 2014.

3.3.1:Inclusion criteria

1. The HIV infected adolescents (12-19years) who actually attended the clinic during the study period.
2. HIV infected adolescents (12-19years) who knew their HIV status for at least six months were included in the study. Knowledge of HIV status was defined as knowing the disease by its name.

3. Those who were mentally capable of giving an informed consent or assent.

3.3.2: Exclusion criteria

1. Individuals who were acutely ill or required hospitalization were excluded from the study.
2. Individuals who could not give informed consent or assent were excluded from the study.

3.4:Sampling Procedure

In accordance with qualitative research methods, a purposive sampling technique was used to explore a broad range of disclosure experiences (Carpenter &Suto, 2008).The sampling was done to achieve maximum variation in age and gender as this was supposed to provide a wide range of participant views. A sample of 20 adolescents participated in-depth interviews allowing for a deeper understanding of the perceptions and experiences of adolescents. The information provided from these 20 participants allowed for theoretical saturation to be achieved.

There is a dedicated clinic for HIV infected adolescents at Harare Central Hospital. To recruit patients the researcher went to the clinic in person. Those participants who met the inclusion criteria were invited to participate in the study. The purpose of the study was explained to them. All the participants were asked to sign an informed consent/ assent form before participation in the study. Participants were provided with two consent/assent forms, one in the local language (Shona) and other in the English (see appendix III and IV for consent and assent forms).Those who were under18 years of age were asked to sign an assent form and then consent was sought from the parent or guardian. A brief demographic questionnaire was administered to all participants. This was followed by an in-depth interview to cover a core set of topics, lasting 45 minutes to an hour. The interviews were conducted in either English or the local language (Shona) depending upon the preference of the participant. The interviews were conducted by the principal investigator who is a psychiatrist and a research assistant who is a social scientist. All interviews were audio-recorded and later transcribed verbatim. All interviews were conducted in a private room dedicated to the study team, with confidentiality assured. All participants were given 3 USD as a token of appreciation.

3.5:Data Management

Written notes were taken to document any non-verbal cues. The first four interviews that were conducted in the local language (Shona) were transcribed in the language of the interview. This was followed by translation of the Shona transcripts into English. The English translation was done by a bilingual speaker from the Linguistics Department of University of Zimbabwe. After confirming the good quality of transcription and translation, the rest of all the Shona interviews were translated and transcribed simultaneously. All the interviews conducted in the English language were transcribed as such. Each participant was given a unique identification code and all the identifying information was removed. All the demographic information was captured using Microsoft Excel.

3.6: Instrument

Disclosure to others was defined as " autonomous revelation of one's HIV status to family, friends, partners or units of society"(Adejumo, 2011). The interview was guided by an interview guide with themes arising from a literature search and after consultation with stake holders including HIV care physicians, nurses and counsellors. The interview guide contained open ended questions regarding adolescents' ideas about disclosure, about their own disclosure experience and the perceived barriers and facilitators of disclosure to others. The questions were followed by suitable probes to assist and explore the relevant issue. Rapport was established with the participant to assist him/her to open up. The interview guide was translated into the local language and back translated to ensure validity. The guide was piloted on 2 participants and the weaknesses identified were corrected in the final interview guideline. All the interviews were conducted by the principal investigator and a qualified bilingual research assistant (see appendix I for the interview schedule).The interview guide was further facilitated by the use of emotion maps. These are pictures which were designed by a local artist and show a range of different emotions for example sad, happy, afraid, confused etc. These pictures have been used among HIV infected children aged 11 to 13 years participating in the ARROW study which was looking at the social and economic realities of Paediatric ART in Zimbabwe and have been found to be helpful to explore the feelings of adolescents which might not be very expressive due to their age

and verbal skills (personal communication with Zivai Mupambireyi). Different emotion pictures have been included in Appendix I.

3.7: Data analysis

The qualitative data analysis for this study was conducted using the framework approach (familiarization, identifying a thematic framework, indexing, charting, mapping and interpretation) (Gale et al., 2013). The framework approach was used as it is one of the qualitative data analysis technique which allows qualitative data to be analyzed systematically. Moreover, the framework approach was chosen as there is already some date available and this approach helped me to compare themes emerging in my data set with relevant available information (Gale et al, 2013).Initially, transcripts were read to familiarize myself with the data and any additional information including any expressions or body gestures. After familiarization, transcripts were read line by line for emergent themes, which were then coded. Care was taken to ensure the codes accurately captured the respondent's meaning. A second researcher independently coded the interviews to ensure the validity of the categories. After coding the first 3-4 transcripts, both researchers compared the codes and then final codes were given after agreement was made between both researchers on the specific codes Subsequently these codes were used as a framework to code the remaining transcripts. N-Vivo 10.0 a qualitative software program was used for data analysis (QSR international, 2012).

3.8:Ethical consideration

A number of ethical considerations were addressed for this study. First, written consent was asked from all participants who were 18 or 19 years old and parents/guardians of the participants who were less than 18years old. Written assent was asked from all less than 18years old and confidentiality was assured. Second, the participants were assured that their participation in the study was voluntary. They were assured that if they want to withdraw at any point during the study, they can do so and their information would not be included in the study. Third, all the study materials were coded to ensure confidentiality. All the questionnaires, consent and assent forms and coding information were locked in a drawer in the Department of Psychiatry, University of Zimbabwe College of Health Sciences, with keys kept by the researcher only. Data were entered into a computer with password known to the researcher only. Fourth, the

participants were offered 3 US dollars as a token of appreciation for the participation in the study. The participants were reimbursed the travel expenses if they had to return on a later day to participate in the study.

Ethical approval of the study was obtained from the Joint Research Committee of Harare Central Hospital, Medical and Research Council of Zimbabwe and Human Research Ethics Committee of the University of Cape Town.

CHAPTER 4: RESULTS

The results of this study are presented according to the following categories: 1) Characteristics of study participants, 2) Participants' HIV knowledge and emotional adjustment after HIV status disclosure, 3) Adolescents' general views about status disclosure to others, 4) Barriers and facilitators of status disclosure, 5) Disclosure experience, 6) Disclosure strategies, 7) Advantages of status disclosure to others.

4.1) Characteristics of study participants

During the study period, 20 adolescents between the ages of 12 and 19 years were interviewed by two interviewers. Among the participants, there were 11 males and 9 females. All were on antiretroviral drugs and all were attending school. Seven were double orphans (both parents were deceased), ten were single orphans and three had both parents alive. Nine were living with one parent, ten were living with other relatives and one was living alone. Six had attended a support group sometime in his/her life. Age of disclosure to them ranged from as young as 4 years to 14 years. Most of the participants admitted to be infected vertically, where one felt he got HIV from a contaminated injection and one other participant was not sure about the route of acquisition of HIV. All socio-demographic and practice characteristics are shown in Table 4.1.

Table 4.1: Socio-demographic and practice characteristics of adolescents

Characteristics	**N (%)**
Gender	
Female	9 (45%)
Male	11 (55%)
Current school attendance	20 (100%)
Parental status	
Double orphans	7(35%)
Single orphans	10(50%)
Both parents alive	3(15%)
Currently staying with	

Both parents One parent Other relatives Alone	0 9 (45%) 10 (50%) 1 (5%)
Age in years	12-19
Age in years of disclosure to adolescents	4-14

4.2:Participants' HIV knowledge and emotional adjustment after HIV status disclosure

I will first describe participant's knowledge about HIV and then their emotional adjustment after HIV status disclosure to them.

4.2.1: Participants' HIV knowledge

HIV knowledge was explored regarding routes of transmission and general information about HIV infection. Most of the adolescents admitted to be informed about the routes of transmission of HIV. They gained this information from different sources such as school teachers, clinic staff as well as from family. They described different routes of transmission of HIV infection including mother to child transmission, breast feeding, through sex, sharing razor blades and using contaminated objects like syringes. However, some of them have partial knowledge about HIV transmission. For example, some participants thought that sharing a blade or having sex were the only possible routes of HIV transmission. One adolescent described several ways of HIV transmission where on further questioning, it became clear that he had no idea what the words mean as shown in the following quote:

> *{People get HIV}Through hugging, through kissing each other,{I thought about it myself as} You see pictures in books. {Moreover people get HIV} through sex and through abstinence". (Male, Age 13yrs)*

Another adolescent mentioned that he thinks he didn't get HIV from his parents, although both his parents were HIV positive. This is evidenced by the following quotation:

"Maybe (possibly) it could have been caused by getting injections used on people who had HIV. Why I think it (mother to child transmission)didn't happen in my case is because my younger brother is HIV negative". (Male, Age 18yrs)

While exploring general information about HIV infection, there were some positive and negative findings. Among the positive findings, participants mentioned knowing some important concepts about HIV/AIDS, like the HIV virus weakens soldiers (defense) of our body and knowing the difference between HIV and AIDS:

"I didn't know HIV and AIDS are different. I just thought it is the same. People say a person who is HIV+/ AIDS is totally dead".(Female, Age 19 yrs)

"Some can say, people living with HIV are about to die. Because they (school fellows) don't understand, they think HIV is like death and people are sick. {We should make them understand by} telling them what is HIV and the difference between HIV and AIDS. HIV is a virus that causes AIDS. {You can prevent AIDS} by early detection and treatment".(Female, Age 18 yrs)

However, among the negative findings certain knowledge gaps were identified. These include confusion between the concept of treatment versus cure of HIV infection, travel restrictions due to HIV infection, HIV transmission risk in a potential sexual partner and some religious myths. One adolescent heard in the community that people with HIV infection are not allowed to travel outside the country:

There is this other thing that people with HIV are not allowed to go outside the country [laughs] I asked my friend 'Is it true that?' And she was like 'Not sure' . I even wanted to ask my Doctor but the time when I came I forgot to. So I said 'Are they telling me that I'm going to die in Zimbabwe or what?'For me I was ever worried because I thought that would be total discrimination of the people".(Female, Age 18 yrs)

There were some interesting religious beliefs. Two participants mentioned that according to the

teaching at their Church, HIV can disappear by praying, as narrated in the following quote:

"Diseases like cancer, HIV and all sorts of diseases, I don't believe that they are diseases. I believe that they are (evil) spirits because God didn't create us with all sorts of diseases. These diseases are being caused by evil spirits, for example at PHD Ministries you see all sorts of diseases going."(Male, Age 17 yrs)

Lastly, while discussing future family and children, one adolescent felt that there is no possibility for his partner or wife to be HIV negative as borne out by the following quote:

"Aaahhh, they (my wife and my children) will not be negative but I think they can just live a life that make people get by."(Male, Age 17 yrs)

4.2.2 Emotional adjustment after HIV status disclosure

After exploring HIV knowledge, the next step was to explore the emotional adjustment of HIV infected adolescents after HIV status disclosure to them. Most of the adolescents expressed initial emotions which changed and became positive over the passage of time. This adjustment seemed to be facilitated by findings answers about "acquisition of HIV infection" as well as "support" from family, friends and counsellors as described below:

" At that time I didn't feel anything. I just said that is what it is, so let it be. But I got stressed as time went by. It started haunting me that how am I going to live now that I know my status. But right now I am ok because I have got comfort from my counsellors, and as well from my friends".(Female, Age 18 yrs)

"For a few days I was angry I think for 1 month and I came here and I asked my counsellor and she told me that you can get HIV from your mother and she asked me how my mother died and I told her that my mother was sick. And she said maybe you got HIV from her. Now I don't have any problems because I understand my status and I know how to live with HIV and I have counselling each and every time when I have a question I ask my counsellors". (Female, Age 18 yrs)

Where some adolescents showed positive emotional adjustment with time, some participants continued to struggle with accepting their HIV positive status:

"It still hurt(s) as my friends don't take it (drugs)"and "it hurts me that the HIV I have I didn't get it on my own".(Female, Age 16 yrs)

In the next section I will present the findings regarding the adolescents' views on HIV status disclosure.

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4.3:Adolescents' general views about HIV status disclosure

When asked about their views about HIV status disclosure to others, adolescents generally thought that disclosure was very difficult. They gave different reasons such as it's a part of their life and that disclosure is not necessary and it's none of other's business. However, adolescents admitted to facing difficult situations, where they have to explain to others, the reasons for missing school for clinic reviews or acute illnesses as well as explaining the reason for taking medicines. To avoid disclosure at school, participants adopted different ways, which include asking for review dates when they are free from school or making excuses and lying. Some of these conflicts are mentioned in the following quote where one adolescent expressed her dilemma before disclosing to her friend:

"It just came through my mind and I just decided that I must tell her because she was worried why I had to leave school, at a boarding school to go home for reviews. So every time I would leave school maybe 3 times and she would ask me what the review was about. At times I used to say ulcers and she would say 'ok, fine'. She was ok with that but I just decided to tell her the truth because I don't feel like lying to everyone".(Female, Age 18 yrs)

Similar dilemmas affected adolescents at home. Issues about taking medication or going to the hospital became important concerns when family members were not aware of their status. One

adolescent mentioned that his stepmother was not aware of his status and he has to hide his pills between his clothes and in order to come for clinic review, he has to go an extra mile:

"I start by going to Lochinvar where my mother's sister stays for the weekend then I come here so she (step-mother) doesn't know that I came here." (Female, Age 16 yrs)

With regard to romantic partners, adolescents expressed different concerns. These concerns were often associated with the fear of not wanting to disclose, or around occasions when a partner may ask for sex without knowing their status or the consequences of sex without status disclosure. This made them feel guilty and participants constantly questioned themselves:

"At times when I'm meeting as teenagers {out on a date}, I feel guilty. It's not like I had sex with him but I just feel guilty. 'What if he asks me for sex, what will I tell him?' I just feel guilty, at times I just feel like 'should I tell him, should I not' and the thing is still haunting me".(Female, Age 18 yrs)

Where some participants were totally against the idea of disclosure, most of the participants admitted to thinking about disclosing to others. They thought that they will eventually disclose when their fellows are more understanding, when they will be independent or are about to get married, or are more mature and will know how to express themselves better. The following quotes express their sentiments about disclosure:

"When I see that they now understand about HIV, I can tell them. When they stop discouraging people living with HIV or when they can learn about HIV." (Female, Age 18 yrs)

"When I grow up, I would say come and hear to my story. Then I will say I have this and that disease. I have HIV, if they don't want to play with me, I can take care of myself because I will be working."(Male, Age 14 yrs)

4.4 Factors associated with disclosure to others

While some participants insisted on non-disclosure of their HIV status (6/20), there were others who admitted that they are thinking about disclosing to others. Different factors were found to be linked to this decision making process and these factors can be grouped into barriers and facilitators.

4.4.1:Barriers to status disclosure

Findings of this study found a number of external barriers often associated with others and with society in general. Among the barriers associated with others, the following factors were mentioned: peer pressure, fear of rejection by others, fear of breach of confidentiality and familial factors. Details of these factors will be described in turn.

Peer pressure was mentioned as an important barrier to status disclosure. Adolescents mentioned an important aspect of being an adolescent, where peers become the most important relationship and they want to avoid things that make them behave differently from their peers. The importance of peer pressure is shown by the following quote:

> *It is something which will make you feel so worried that you will think of not drinking that drug because some of your friends are not drinking it. So you will be following your friends what they will tell you". (Male, Age 14 yrs)*

The fear of rejection by friends and romantic partners was noted as an important concern. They mentioned possible rejection by their friends related to the fear of contracting HIV, in the form of avoiding them or refusing to play with them or losing friendship. These fears are evidenced in the following quotes:

> *I ask myself, "How will (my friends) they react? How will they (my friends) see [view] me when the sun rises or when we meet how do they see me. I feel like maybe they will be scared of me … that this guy will get us infected too… I feel like it's cool the way it is". Male, Age 17 yrs)*

A 19 years old female was rejected by her boyfriend and she remembered he saying, "We are no longer lovers, don't ever call me' then I asked him why? (And he said,) 'Don't ever ask me, just have a relationship with someone who is same to you. A person who is HIV+, I cannot get married to person who has HIV". (Female, Age 19yr)

Fear of breach of confidentiality was noted as a significant concern by many participants. Adolescents mentioned people divulging their information without asking their permission. They mentioned relatives as well as teachers disclosing their information and resulting in unnecessary disclosure to others. This is elicited by the following quotes:

"There are some people whom if you tell them, they laugh at you and go round divulging that information saying 'look at her, this is what she is."(Female, Age 16 yrs)

"If you tell them (teachers) what you are, they (school) can give you as an example at the Assembly." (Female, Age 19yrs)

Familial factors affected the adolescents differently. Many participants mentioned having no discussions with their family. However, other participants had both positive and negative input from their parents. On one hand, some adolescents were actually helped by relatives in deciding who and when to disclose their HIV status, while others mentioned their family inhibiting their decision to disclose. Family often conveyed such messages in two ways: a subtle message to keep HIV a secret or threatening consequences which may occur. These factors are shown in the following two quotes:

"Some people will say it's just for you, don't tell people" Male, Age 14 yrs)
"As a child you will be afraid that your mother might not want to tell your relatives and if you do that, you can be in trouble with her."(Female, Age 15 yrs)

Stigma was mentioned by many participants as one of the most significant societal factors affecting status disclosure. These findings will be discussed first by describing a lack of knowledge about HIV as a possible reason for this stigma, and secondly different stigma

experiences. The adolescents in the present study mentioned that a lack of knowledge was one of the main reason for others 'stigmatizing attitudes towards people living with HIV as described in the following quote:

"People discriminate HIV positive, because many of them, they don't know the ways in which people can get infected, they think that if I give you a hand shake I will spread so..."(Male, Age 13 yrs)

Many adolescents referred to the community in general and their peers, specifically, as knowing very little about HIV and its transmission. In the community HIV is considered equivalent to death, and this is a result of a lack of knowledge of the distinction between HIV and AIDS. These sentiments are depicted by the following quotes:

"People say a person who is HIV+/ AIDS is totally dead."(Female, Age 19 yrs)
"People say, 'When their status is disclosed, people with HIV don't live longer than 10 years, they only live for 3 years"(Female, Age 18 yrs)
"They will say to a boy who has fallen in love with HIV positive girl, 'So you love a person who has HIV?[Are you crazy?]Do you want to die?'"(Female, Age 18 yrs)

Moreover, adolescents felt that the ignorance of the community regarding different ways of non-transmission of HIV, has the potential to lead people to discriminate against others:

"I think she (my aunt) thought that I could transmit the HIV virus through touching things but that was not correct."(Female, Age 19 yrs)

Adolescents indicated that the fear of community's discriminatory behaviours prohibited them from disclosure. They felt angry with people who were spreading wrong information about HIV. However they avoided talking even in general about HIV, despite having superior knowledge:

"Some of my friends at school just say 'aaahh', they just discourage [denigrate] people with HIV, they discourage the disease [denigrate]. I feel that one day when they realise that I have HIV, they won't even greet me."(Male, Age 17 yrs)

Discrimination was reported in the form of witnessing as well as experiencing discrimination. Most of these discriminatory behaviours were shown by children and adolescents towards their peers at school as well as in community. Discrimination happened at times without knowing other's HIV status. The school children or other individuals in the community will look at them and see some symptoms linked with HIV and will tease them. One such behaviour is described in the following quote:

"There is this girl in our class. So when there is a problem, they just say 'Aaahh you're HIV positive' and she says ' aah why are you saying that?'They say 'Look at yourself your hair are frail, Your body is too weak, even you've got these skin disease, skin rashes".(Male, Age 17 yrs)

These discriminatory behaviours included teasing them about their status, telling them their opinion doesn't matter due to their HIV status, prohibiting them to touch things or avoiding physical contact, like shaking hands. These discriminatory behaviours are described in the following quotes :

"If you don't agree with them on a point, they say 'who are you to say that, you've got AIDS."(Male, Age 17 yrs)

Another adolescent mentioned discriminatory behaviour towards his sister :

"My younger sister told the people about her status as she was young and they started saying 'You have AIDS' and she would cry. It's difficult. That's why I think keeping this a secret is better than telling people."(Female, Age 16 yrs)

Some other participants revealed discriminatory behaviours they experienced themselves. Adolescents experienced discrimination at school as well as at their homes. These discriminatory

behaviours included teasing them about their health or taking tablets or forcing them not to touch things and burning their clothing in fear of catching HIV infection. Some of these behaviours are reported in the following quotes:

"Some children who I play with used to say: 'Look at her, she is sickly'. They would say, 'You go and get you tablets.' It used to hurt me a lot." (Female, Age 15 yrs)

"She(step mother) never wanted my pants to mix with her or her children. She would say I would spread HIV to her children. She burnt all my pants that were at home saying that I will infect her children with HIV." (Female, Age 14 yrs)

Some participants experienced discrimination when others only suspect them of having HIV:

"I don't have friends. The one that I have, if I go to play with her she just 'scratches' me and goes to play with others. If I go to her she says 'Your sister died of HIV and I don't know if you have HIV too."(Female, Age 16 yrs)

In summary, an interplay of the lack of knowledge and stigma and discrimination prevented self disclosure of HIV status to others. Lack of knowledge was evident at several levels including community in general to family, peers and teachers.

4.4.2: Facilitators of status disclosure

Different factors have been identified as facilitating disclosure at the personal, relationship and community or societal level. Participants described factors which have facilitated their own disclosure, as well as factors which they feel will help them to disclose in the future. Adolescents described personal facilitators which can be classified as autonomous factors: gaining independence and having better communication skills. These factors influenced the participants' planned timing of disclosure. Further motivating factors were described and include being honest with their friends, acquiring more information, possible hope for their future, and finally an altruistic motive of educating and helping others.

The desire to be honest and gain a closer relationship with friends is described as a facilitator in the following quote:

One adolescent said that not disclosing to his friend makes him feel like: "I am not able to be (a friend just as I should be to him) [an honest friend]".(Male, Age 17 yrs)

One adolescent expressed a need to know more about HIV transmission risk to her future partner and children and felt that positive responses will give her hope:

> *"Am I able to have children? Is it possible for my child to be HIV- or my husband to be negative? And then the way they would respond to me, will make me feel good."(Female, Age 19 yrs)*

A few adolescents expressed an altruistic motive for self-disclosure; they felt that their disclosure can stimulate others to go for testing. They further emphasized giving others hope about HIV:

> *"I want to tell other people that your HIV+ status does not mean that you are dead. You have many years to live. Any HIV+ person has an advantage to a person {who} does not know their HIV status."(Female, Age 18 yrs)*

Adolescents wanted to disclose when they are older. They felt that being independent and having better communication skills will assist them in disclosing.

> *"I will tell others when the time will be right, around age 19 yrs, because I will know how to say it." (Female, Age 16 yrs)*

> *"I will call you {my friends}, I would say come and hear to story here, then I will say I have this and that disease. I have HIV and if they don't want to play with me, I can take care of myself because I will be working". (Male, Age 14 yrs)*

Adolescents mentioned different factors associated with others which would facilitate disclosure and these included the nature of the relationship, the length of time they have known that person, the qualities of a person, and known HIV status. While talking about the nature of relationship, adolescents felt it was especially difficult to disclose to their friends, romantic partners and teachers. HIV was considered by some as a secret which should be limited to the family and very close friends. Adolescents mentioned some important characteristics that helped them decide when to disclose to their friends as mentioned in the following quotation:

"The character of a person depends on being reliable and understanding and reading the Bible. The thing I consider when choosing a person is the attitude. If a person has an 'attitude of gossiping' that person is not good. The other person who is quiet and keeps secrets, you can tell him." (Male, Age 14 yrs)

Some adolescents felt disclosure to friends is possible depending upon the length of time you have known that person and if he/she is trust-worthy. These sentiments are expressed in the following quotations:

"I will say you can disclose to {a} person you trust and must be a very good friend. I will say wait a bit in disclosing until you have given yourself time to learn more about your friend, is she not going to disclose the information to others at home [without your permission]. You can give an example of an experience of another person and see how she reacts."(Female, Age 15 yrs)

With regard to romantic relationships, many adolescents said that they are not involved and are actually afraid of getting involved in a romantic relationship. Disclosure to a partner was their main concern for avoiding these relationships. This dilemma is depicted in the following quote:

One adolescent felt it is important to tell your partner:"she might be negative and you will be positive and if she gets it that you are positive, it can ruin your relationship or she can kill herself."(Male, Age 18 yrs)

Only a few adolescents admitted to being in a romantic relationship and they said they will disclose when they are about to get married or before having sex. One participant disclosed to her boyfriend as he was pushing her for sex.

"At first it was not easy but he continued pushing me for sex. I decided to tell him. He must know because he was continuously saying 'I want to sleep with you, if you love me you must sleep with me' then I said 'I cannot do that, it's not possible.'" (Female, Age 19 yrs)

Finally there are some community/societal facilitators that have been identified in this study. These factors are divided into supportive bodies and improvement in knowledge about HIV. Supportive bodies include media, religion and role of health care workers and support groups and will be mentioned first. Later, I will mention the findings on improving societal knowledge. While discussing the importance of supportive bodies as a facilitator of disclosure, one adolescent mentioned importance of media. He mentioned feeling inadequate and reluctant to disclose to his friend. But when he heard a big local star going public about his HIV positive status, he decided to tell his friend. His story is depicted in the following quote:

"It was due to advertisement on the TV(and) radio about HIV status, this comforted me and it gave me the courage to easily tell my friend. For example I can sit and watch Oliver Mtukudzi. He is the biggest local artist and he is HIV+, he can encourage people who (are) HIV+ .He advises that you must be open with your status because you're not different to those who are HIV-. We are all people".(Male, Age 19 yrs)

Religion was mentioned by a few adolescents, but mainly as a way to help them cope with HIV. However, one adolescent explained how his religious beliefs helped him with disclosure. He felt that the way his pastor approached him, made it easy for him to disclose:

"I still remember in 2010, there was a church meeting in South Africa that I missed; then they called me saying 'Where are you? We need you here.' Then I said, 'No I am not at home, I am admitted at hospital.' They said, 'What happened?' and I said, 'There are some issues I am fixing,' and then they said, 'We are coming there.' Then my Pastor came

and he said that, 'We need to know what is happening to our child because when you are in my church, you are also my son,' and I said, 'The thing is I am HIV+.' He just said, 'It is well; In God we trust. All things will work together.' That was his response." (Male, Age 14 yrs)

Furthermore, the religious teaching helped him to allow his status to be disclosed to 10 more church friends, as in their church they believe health and illness is from God which makes them work together.

"My Pastor told them that, 'I went to see one of our leaders and he told me that he is HIV+.' In our church we say that 'all things are of God' and we give praise to God for all things. So if this is HIV, it belongs to God.'"(Male, Age 14 yrs)

Finally, adolescents expressed the importance of support groups and health workers as a facilitator of status disclosure. Adolescents shared different ideas when they were asked about the role of clinic staff (health professionals and counsellors) and support groups in the disclosure process. Firstly, I will describe their ideas about discussions with the clinic staff, although many participants denied ever talking to clinic staff about disclosure. One participant expressed the reason for not discussing status disclosure with clinic staff:

"Eeeemm I thought maybe I will find a solution myself but just now I am realising that maybe I don't have the answer." (Male, Age 17 yrs)

Some participants did get some useful advice from doctors and counsellors. This advice ranged from general advice to more specific advice about disclosing to different people involved in various relationships with the participant and reasons for disclosure. One adolescent was generally advised by a doctor that he should choose the "right time" and "right person" to disclose to. More specific advice was given about disclosing to the relatives, friends and romantic partners. The advantages of status disclosure were described as medicine reminders, reminders for clinic reviews and safe sex. Clinic staff gave the following recommendations:

"You can tell some people because it makes it free for you to take your tablets anywhere because everyone knows. Even at church, at school."(Female, Age 18 yrs)

"They (counsellors) just say you should tell your girlfriend that you are positive and you should use condoms and that you should tell your close friend."(Male, Age 18 yrs)

Another participant asked for a doctor to help explain to his friends about HIV as he felt that his friends wouldn't believe him:

"When she gets sick she can go to the doctor and the doctor will tell him {her} and talk to him{her} to know that HIV is not... that HIV cannot be cured but cannot be passed through playing when she {was} told {by} someone who is like doctor, she can accept and then she can come back and play with me." (Male, Age 14 yrs)

Secondly, when asked about the importance of support groups in the disclosure process, adolescents found them beneficial. Some of these participants have actually attended support group and got helpful advice about other issues linked with HIV and felt that support groups are an important resource to help them disclose to others. Some participants got specific disclosure advice from support groups:

"Some {support group say}tell their {your} relatives just in case your parents die, you may fail to get anyone to take care of you. They {support group} say at times you are not supposed to tell because people may be scornful at you." (Female, Age 15 yrs)

"Yes they {support group} advise. They advise that we should be free or comfortable, {as} being HIV does not mean that you are isolated. They say that tell someone who is 'open' to you. Who is concerned about you." (Male, Age 19 yrs)

When specifically asked about what will they need to assist them in the disclosure process, the adolescents felt that knowing how to choose the right person, how to effectively communicate to them about their status and how to cope with the disclosure outcome would be beneficial. Most

participants wanted support groups to assist them in making these decisions. One participant insisted on a one to one discussion with a health professional as he felt some questions cannot be discussed in front of other people. The following quotes represent their disclosure needs:

"I think they {support group} help you to talk to anyone you do not know and to even know how to speak to him or her in a positive way where he doesn't get confused of what you are saying." (Male, Age 18 yrs)

"Uumm, I'll benefit {from support group}like… maybe {knowing} how they feel when others discourage them, how they tell others that they are positive." (Male, Age 17 yrs)

One participant wanted the support group to be at the hospital and not in the community. He felt, if the support group is in the community, it will be hard for him to open up as he won't know about the status of others.

"Because here you will be knowing that everyone is +HIV and they will teach them how to tell others on their status, rather than in the community you will not know which one is positive and which one is negative."(Male, Age 18 yrs)

Finally, the improvement of societal knowledge was considered an important facilitator. Participants felt frustrated how the community in general and specifically school children felt about HIV and people suffering from HIV. They wanted to educate them about HIV and emphasize the difference between "HIV" and "AIDS". Adolescents wanted to change the image of HIV infected people:

One adolescent said she wants to tell her school fellows:"Do you know that if you have HIV it doesn't mean you will be skinny, you won't be healthy, not be attractive but you will be OK and you're just like someone who is negative." (Female, Age 18 yrs)

Another adolescent expressed his desire to tell his class fellows: "(if a) person is positive or negative he can play with each other because it cannot be passed by playing."(Male, Age 14 yrs)

4.5: Disclosure experience of participants

The disclosure experiences of participants were explored; active, third party and accidental disclosure was reported. Third party disclosure happened when family, friends, teachers or others disclosed the participants' diagnosis to others. Most of the participants admitted to their relatives knowing about their HIV status. They described different situations where doctors, parents or main caregivers disclosed their status to others which all linked to the main theme of adolescents being dependent on others. Their status was disclosed by health professionals to their relatives when they visited the hospital due to an acute illness. Some other situations which led to disclosure by their parents included: parents arranging for their care with other relatives in case of parental illnesses or when parents were not available to supervise the taking of their medication due to work commitments. Moreover, when parents were not alive and other relatives had to take care of them, third party disclosure occurred. The majority of participants were not asked for their consent before this disclosure happened, in fact only one participant admitted to parents talking to him before disclosing his status to his brothers. One such situation is described below:

> *"She (my mother) knows. She is the one who told her sisters and brothers that when she became sick, she tested HIV positive. She was asked, 'What about your son?' She said… 'I was tested… maybe soon I will be dead. You guys look after my son. He takes pills.' So when I visit them, everyone knows that 'he takes pills.'"(Male, Age 17 yrs)*

Adolescents also differentiated between necessary and unnecessary third party disclosure. Two adolescents mentioned unnecessary disclosure in the form of a relative disclosing their status to anyone who cared to listen. However, some adolescents actually felt supported by the extended family after disclosure as explained by one adolescent:

> *"The way she (my aunt) told them (the rest of family) everyone was there, 'There nothing different to how she was living in the past, all is the same.' She just knew that people will not understand and that people don't know the difference between HIV & AIDS. I was ok*

because if the person did not know and they have visited here, you would not feel comfortable with the visit or to visit him or her." (Female, Age 19 yrs)

Some adolescents mentioned accidental disclosure as others saw them with antiretroviral drugs:

One adolescent was actually surprised about her aunt knowing about her status and she remembers her aunt saying to her:"I know you're HIV+ because you're taking these drugs." (Female, Age 18 yrs)

Some participants admitted to making a conscious choice and actively disclosing to others. Adolescents disclosed to different people like family members, friends, teachers, pastor and boyfriends. They described different circumstances which led them to disclose to others. Family disclosure happened in order to explain their reasons to take medicine, or under circumstances where they had to move and stay with different relatives. Decisions to tell friends were not easy. Many adolescents in the study reported thinking for a long time before actual disclosure. In most cases, they randomly chose a day or shared their information while discussing problems and in a few cases it took prompting from friends.

"One day at school I fell down because I was losing a lot of power. They (friends) took me to the Senior Teachers' office and they drove me home. They then came to my house the next day and asked me to tell them about myself: 'Tell us about your life.' Then I told them 'I'm HIV+.'" (Male, Age 14 yrs)

Disclosure to a romantic partner was found to be the most difficult decision. One participant actually disclosed to her boyfriend after thinking about it for a long time. She mentioned her situation:

"One of the days he just looked me in my eyes and said, 'Why do your eyes have tears?' and I said, 'Nothing.' Then he asked again and I said nothing and he said 'You have something you want to tell me but you don't want to say it; I want to know.' Then I told him at that moment and he took it the easy way and said, 'It's OK; it happened,' and he said are we able to go and get tested?'" (Female, Age 19 yrs)

In the next section, I am going to describe the disclosure strategies of the participants as described by them in this study.

4.6: Disclosure strategies

Once adolescents decided to disclose, they adopted implicit and explicit strategies to disclose. Many participants disclosed explicitly by telling others the name of the disease. While others used the implicit strategies when they did not have the strength to tell others directly. Implicit strategies included: taking their tablets openly in front of other people or giving their test results to their relatives. Finally, some adolescents adopted different ways to assess the response of their friends before disclosing to them:

> *"Well I just asked her: 'How would you feel if someone that you love is HIV+?'and she was like, 'Nothing, I would just have to comfort that person and tell her about how to live life and how to stay safe always,' and she even comforted me at that time and then I was like, 'Ok, so the thing is do you know that I'm HIV+?"(Female, Age 18 yrs)*

Those adolescents who did not disclose, suggested different strategies to disclose. These strategies included explicit and implicit strategies. Explicit strategies were conceptualized on one main principle of clearly communicating the way of acquisition of HIV infection. Adolescents mentioned disclosing to their friends about their status when they will be learning about HIV/AIDS at school. These explicit strategies are presented in the following quotes:

> *"I want to tell him (boy friend) that my mother is the one who gave me HIV and I was born with HIV." (Female, Age 16 yrs)*

> *"I will just say… or it will start as… or you will be studying… or you will be doing the subject that has those similarities and you tell him that this topic I know it very well because from where I go every month at hospital they teach us every day because I am +HIV. That is how I would tell him." (Male, Age 18 yrs)*

Some implicit strategies were suggested by the adolescents which included: going with the partner for HIV testing or talking to them about HIV and assessing their knowledge about people living with HIV as shown in the following quotes:

"(You can ask your friend): 'Are people able to survive HIV?' And then the way s/he responds to me saying, 'Some people live long lives; you can be able to live the way you want; you can be able to do anything you want,' I just think it better to tell." (Female, Age 19 yrs)

"There is one day when we (me and my friend) were comparing the latest Ebola virus and HI virus…saying… 'If you were to choose one disease, which one would you choose?' Then he say(s'), …aah… I will choose HIV virus because it's like there is a cure.' That's the time I realised that maybe I tell him". (Male, Age 17 yrs)

Adolescents also mentioned telling their friends a story and assessing their response. They suggested that they should disclose to others if they observe a positive response in the form of understanding and compassion about HIV infection as alluded in the following quotes:

"You will see the way he will speak like if you say, 'That person is HIV+ and I want to play with her,' – you will see how he responds. (If he says) 'You don't laugh at her; you don't know maybe she got HIV through birth or maybe she got HIV through her breastfeeding mother.' (But)If he responds and says, 'Don't play with her; you will get HIV also, you will know that you must not tell this person." (Female, Age 16 yrs)

4.7: Advantages of status disclosure

In this study adolescents mentioned several advantages of status disclosure. These advantages include social support and medication reminders. Social support included emotional support, financial assistance as well as assistance during times of emergency. They received

psychological support in the form of acceptance of their disease and assurance of maintaining various relationships:

"When I told him (my brother) the truth, I thought that he would just say, 'You are no longer my brother now,' but he loves me more than he did." (Male, Age 13 yrs)

One adolescent got a good response where her friend told her: "You're still my friend as it is; HIV is just a disease - it doesn't take friendship away." (Female, Age 18 yrs)

"My relatives said that it was not my fault; it was my father's and mother's issue. They were comforted by counsellors." (Male, Age 19 yrs)

Several other advantages of disclosure were mentioned as well, like medication reminders, reminders for hospital reviews, financial support like payment of bus fare and providing them with nutritious food and comfortable bedding. Moreover, they reported that they won't be marked absent from school, if they disclose to a teacher or headmaster. Some of these advantages are expressed in these quotes:

One adolescent felt telling friends will be helpful as: "When my parents die or something [like this happens] they will still understand. They will support me to continue taking my tablets." (Male, Age 18 yrs)

It's more like support for you because they (relatives) remind you of your tablets and you don't have to hide." (Male, age 17 yrs)

Participants revealed another important factor linked with thoughts of getting help in case of emergency. This applies to disclosure to both parents as well as friends.

"We are always with friends so if they know your status, in case of emergency, she will know the quick medication or the first steps to take." (Female, Age 18 yrs)

Thus, the participants provided rich data regarding status disclosure to others, barriers and facilitators of status disclosure, disclosure experience, disclosure strategies and advantages of

status disclosure to others. Moreover, there is an indication that adolescents views and practices about HIV self disclosure to others can be influenced by how their status was disclosed to them and what kind of support did they receive after knowing their HIV status. In the next chapter I will present the main findings and discussion of these findings according to the study objectives.

CHAPTER 5: DISCUSSION

The aim of this study was to explore the perspectives on HIV status disclosure to others in 12 to 19 year old HIV infected adolescents attending an HIV care clinic at a tertiary hospital in Harare, Zimbabwe. I will discuss the main findings by addressing the study objectives, presented below:

1. To explore the views of HIV infected adolescents on HIV status disclosure to others.
2. To describe the disclosure strategies of adolescents who have disclosed and anticipated strategies for those who have not.
3. To determine the perceived barriers and facilitators of HIV status disclosure.
4. To explore the experiences of HIV infected adolescents with support group and healthcare providers during the disclosure process.
5. Additional findings regarding the lack of HIV knowledge of the participants will then be discussed and possible ways of improving their knowledge will be presented.

During the discussion, I will compare my findings to the international and regional literature, which will then be discussed in light of current policy and practice.. This will be followed by limitations of the study and conclusions.

The main results of this study are:

5.1: Adolescents general view on self disclosure

In addressing objective 1, it was found that adolescents were exploring their disclosure options in terms of if, when and whom to disclose to. Adolescents were generally hesitant to self disclose to their peers and romantic partners. This finding is confirmed by other studies done in high income countries and Africa (Thoth et al., 2014;Siu et al., 2012). However despite being hesitant to disclose, this study showed that most of them were thinking about self disclosure to friends and romantic partners and some have actually disclosed. Those who were thinking about disclosure confirmed the findings of other studies by describing that they would like to disclose when they will be independent or about to get married or when community and peers will be more understanding about HIV(Di Risio et al., 2011;Hogwood et al., 2013;Siu et al., 2012). Moreover,

an interesting finding is those adolescents who had disclosed to peers and especially friends, made this decision carefully and had good outcomes in the form of peer support. This finding can help us draw two important inferences, first HIV infected adolescents are proving themselves to be quite capable of making decisions to self-disclose and secondly disclosure to friends has resulted in well desired peer support. However, this study showed unnecessary third party disclosure as an important concern of HIV infected adolescents. This concern has been noted in a Ugandan study as well (Siu et al., 2012).

5.2:Disclosure strategies

For objective 2, various strategies were described. Like other studies, disclosure strategies included both explicit and implicit, with many adolescents choosing to use implicit strategies to gauge the responses of potential recipients of status disclosure (Siu et al., 2012). In this study, implicit strategies included telling stories about someone with HIV and assessing others knowledge and compassion about HIV. HIV knowledge was assessed on acquisition of HIV, ways of non-transmission of HIV and overall prognosis of the disease. While describing their disclosure strategies, adolescents in this study emphasized that acquisition of HIV virus was not their fault. This finding has been mentioned in another study on the experiences of vertically infected adolescents and was associated with favourable outcomes (Fair & Albright, 2012).

5.3:Facilitators and barriers of disclosure

In addressing the objective 3, various barriers and facilitators were identified in this study. Firstly I will describe the facilitators and then barriers of self disclosure.

5.3.1: Facilitators of disclosure: guidance and support

Adolescents in this study stressed on the importance of guidance and support as a facilitator of status disclosure. This guidance and support was identified as being available from various societal resources. These resources included: health workers, counsellors, support groups, religious groups and media. The adolescents specifically mentioned that support is needed to help them decide about who to disclose to, how to disclose and how to the deal with the

psychological impact after self-disclosure. In other studies, adolescents mentioned the desire to get assistance from health workers in the form of learning communication skills and receiving psychological support (Hogwood et al., 2013). However, disclosure and support/guidance through support group, religion and media has not been explored. Support and guidance from support groups and healthcare providers will be discussed in section 5.4 below. In this section, I will mainly discuss media and religious support. In this study, famous local stars disclosing their HIV status publically was considered a motivating factor to self-disclose. Religion emerged as a factor which can be both a barrier and facilitator to HIV acceptance and disclosure. Where on one hand, some adolescents shared their religious belief about HIV as not a disease but being an "evil spirit" which cannot be cured by drugs but by spiritual powers. On the other hand, one participant mentioned his religious teachings assisting him in HIV self disclosure. He was supported because according to his religious teachings, all diseases including HIV are from God. This religious belief helped him to remove the personal responsibility for the disease and guaranteed social support. Linking religion to promote disclosure might not be that easy and will require further exploration. However, it is important to bear in mind that for many years, religion has played a pivotal role in the lives of the majority of the people in Africa. Religion has been known to guide the everyday life of people and provide them assistance and support during times of need (Lee, 2010) . There are examples of religion bringing dramatic changes in people's lives as for example, Senegal is one of the model countries in their role in HIV prevention programmes. In Senegal, HIV prevalence felt dramatically when religious beliefs were combined with the media (Pesani, 1999). Therefore, it is important to further explore the possibility of religion as a facilitator of HIV self disclosure.

5.3.2: Barriers to status disclosure : stigma , discrimination and lack of knowledge

Many adolescents were fearful of disclosure for a number of reasons: peer pressure, anticipated rejection, fear of breach of confidentiality, family influence to prevent disclosure and stigma and discrimination. These findings are confirmed in developed countries and in Africa (Siu et al., 2012b;Thoth et al., 2014). However one interesting finding of this study is the importance of stigma and discrimination against peers with HIV. This finding is confirmed by the other studies conducted in Sub-Saharan African including Zimbabwe (Deacon & Stepheny, 2007); Campbell, Skovdal, Mupambireyi, & Gregson, 2010). Children have been found to stigmatize their HIV

positive peers in the community as well as in schools. Their discriminatory behaviours are influenced by the attitude of parents, teachers, as well as society in general (Castle, 2004). This study has shown some possible link between ignorance, non-disclosure and discrimination as follows.

In this study, adolescents felt lack of knowledge among community members resulted in stigma and discrimination and this inhibited self-disclosure. Some of these knowledge gaps included limited knowledge about ways of transmission and non-transmission of HIV and the difference between HIV and AIDS. This can be further explained by the community perception of HIV transmission mainly occurring through sexual promiscuity and not much awareness of other routes of transmission. Moreover, adolescents alluded to the fact that society doesn't know the difference between HIV and AIDS and believe that HIV is equivalent to death. These findings are confirmed by other studies where adolescents felt frustrated on the discriminatory behaviours, ignorance related to discrimination and wished for community and peers to know more about HIV(Hogwood et al., 2013;Gillard & Roark, 2012). In the literature, there are mixed results available on the relationship between ignorance and stigma. Where some studies confirmed the findings of this study and reported a definite link between ignorance and stigma, other investigators have stated that there is more to stigma then only insufficient knowledge (Smith, 2013; Deacon & Stepheny, 2007).

However, in HIV stigma intervention studies, it was found that improving HIV knowledge did result in improvement in societal attitude towards HIV in general and stigma reduction. There were two interventional studies conducted at schools: one involved training the school teachers and the other involved training the school children about various aspects of HIV. Both studies showed a positive correlation between improved HIV education and stigma reduction(Klepp et al., 1994;Chao, Gow, Akintola, &Pauly, 2010). In another study conducted in a school in rural China, researchers went on to look at what aspects of HIV education are important and who should be targeted. It was found that knowledge about non-transmission of HIV was significantly associated with stigma reduction (Qin, Yang, Kong, Wei, & Shan, 2013). Moreover, another interesting finding of this study was that positive attitudes of the children positively affected their parents. This finding has important public health implications for the prevention of stigma which

in turn can facilitate HIV self disclosure. While exploring such interventions, it is important to ensure they include children as well as their parents at school.

5.4: The importance of support groups in disclosure

For objective 4, in this study the majority of adolescents expressed their acceptance of support groups as a facilitator of self-disclosure. Few adolescents actually admitted to attending support groups and those who did, described attendance as generally a positive experience. Healthcare providers overall were seen as helpful and supportive and adolescents expressed a wish for increased support from healthcare providers.

Studies conducted among HIV infected adolescents have explored the importance of support groups with reference to decreasing the feeling of isolation and experiencing support (Hogwood et al., 2013). However, support groups and their link with self-disclosure to others has not been explored among adolescents. Among adult HIV positive women, support groups have been found to be one of the most important source of support in general and specifically as a facilitator of status disclosure (Paudel & Baral, 2015). There are different types of support groups mentioned in the literature, some led by health workers like psychologists, counsellors or social workers and others led by peers. Peer support groups are emerging as an important supportive resource with good acceptability among adolescents with chronic disease as well as among HIV infected adolescents (Heisler, 2007;Hogwood et al., 2013b).

5.5:Additional finding: lack of HIV knowledge of the participants

Many HIV infected adolescents in this study showed understanding of HIV with regard to ways of HIV transmission, ways of non-transmission of HIV and the difference between HIV and AIDS. However, a few adolescents showed partial knowledge and confusion about terms such as "Sex" and "Abstinence", and considered kissing and hugging as means of transmission of HIV. Moreover, another participant had no knowledge how to protect his sexual partner. The finding about lack of knowledge about sexual and reproductive health among HIV infected adolescents

has been confirmed in literature (Lee & Oberdoefer, 2009). This lack of knowledge can be linked to despair about the future.

5.6: Implications for policy, practice and research

This study has some important implications for practice, policy and research. Firstly, the finding that stigma and discrimination against peers is an important barrier to status disclosure has important implications. The impact on practice can be through targeted stigma reduction interventions at schools to reduce stigma and discrimination among children and adolescents. Moreover, stigma reduction interventions need commitment from government in the form of policy statements and there is a definite need for more research to find effective ways to fight stigma. Secondly, this research showed a possible link between improvement of HIV knowledge, stigma and HIV disclosure. The link between improved knowledge and stigma reduction has been supported by few studies done in HIV literature (Klepp et al., 1994;Chao et al., 2010), however it requires further exploration. Education on HIV/AIDS has been included in the curriculum of primary and secondary schools in Zimbabwe since 2006 (AVERT, 2012). There is a need to look at the curriculum with the aim of improving on the existing information by emphasizing more on the ways of non-transmission of HIV as well as emphasizing the difference between HIV and AIDS as an effort to reduce stigma. Moreover, if HIV infected adolescents know that they can protect their life partners and children against HIV, this might give them hope for the future and facilitate disclosure. However, this link needs further research.

Finally, several facilitators of self-disclosure were mentioned in this study in the form of societal resources like support groups, media and religion. Media has been used in HIV prevention campaigns with success in Senegal (Pesani, 1999). Now there is a need to explore the role of media as a facilitator of self disclosure. There is a need for further research to confirm the findings of this study and to explore more ways to use media as a facilitator to disclosure. Two studies done in Malawi and Botswana explored mass media as a resource to reduce stigma, thus indirectly facilitating disclosure. In Botswana, HIV stigma was targeted through a television drama based on a family affected by HIV(O'Leary A et al., 2007). They showed a decrease in stigma among viewers following the programme. In Malawi, they introduced a programme called "Radio Diaries" (Creel et al., 2011) and looked at the effects of media on stigma as well as

disclosure. This programme features HIV infected people telling their life stories. They found the programme resulted in a decreased level of stigma, especially among younger participants. However, they did not see any effect on perceived disclosure practices. Interestingly though, they concluded that stigma is associated with non-disclosure and that perceived stigma should take longer time to dissipate. In conclusion, these studies show a positive correlation between mass media interventions, stigma reduction and possibly facilitating disclosure. However, it is important to confirm this relationship by conducting well designed and long term studies to clearly see the effect.

Religion as a facilitator of disclosure is another finding of this study with possible implication on research. This positive correlation arose from the believe that health and disease are from God and this belief helps people to accept others with disease. However, there is a need for further exploration of this finding.

Support groups as an important facilitator of disclosure has important implication for practise, research and policy. Evidence from the chronic disease literature and HIV showed that adolescents find sharing their mutual experience in a support group helpful in improving their feelings of isolation and enhancing their confidence (Di Risio et al., 2011;Mupambireyi, Bernays, Bwakura-Dangarembizi, & Cowan, 2014). Support group led by a professional or a peer have both been found to be effective means of providing support in literature (Menon et al., 2007;Greco P, Pendley JS, Mcdonell K, & Reeves G, 2001). However, in Sub-Saharan Africa where we have limited resources, it is important to choose the strategies which are evidence based, least expensive and culturally appropriate. In Zimbabwe, we have well established community based peer counsellors and psychosocial support groups as for example "Zvandiri" and "Champions for life" (personal communication with the founders of group, Dr. Reid and Nicola Willis). The Zvandiri programme provide disclosure support regarding discussing the legal and ethical implications of non-disclosure to sexual partners, skills to disclose to others and post disclosure counselling. However unfortunately, none of the participants in this study attended this support group which raises a question of acceptability or accessibility of these support services. In my study one adolescent, expressed his desire for such support group services to be organized at the hospital. There is a need to further explore this finding to make the support group service more accessible. Furthermore, there is a need to explore the practises

and measure the effectiveness of the available services. If proven to be valuable, support groups can become an integral part of care and treatment of HIV infected adolescents and can be included in policy.

5.7: Limitations

Several limitations of this study should be considered while interpreting these findings. Firstly this was a qualitative study in which a purposive sampling technique was used and the sample was from a tertiary care hospital. Therefore, it is not representative of the population of HIV infected Zimbabwean adolescents. Secondly, the sample only included adolescents from age 12 to 19 years. Ten and eleven year old individuals were excluded and therefore this study is not representative of the entire group of adolescents. Thirdly the main researcher RK who also conducted majority of the interviews is not a Zimbabwean, believes in Islamic religion and could not speak Shona, the local language of Zimbabwe. This might have brought in some moderator biases. However, there are some other factors which might have modified the moderator biases as for example, main researcher RK is a psychiatrist, trained in effective communication skills as well as residing and working in Zimbabwe for the last 11 years. Finally, some of the interviews were conducted in the local language and were translated to English which can result in some interpretation errors.

5.8: Conclusion

In conclusion, despite its limitations, this study is the first one in Zimbabwe to look at the perspectives of HIV infected adolescents in disclosure process and provides valuable insights into HIV positive adolescents perspectives on disclosure. The most important finding of this study is that the vertically infected adolescents are thinking about disclosure and when, how and whom to disclose to. They have identified several facilitators and there is a need to explore the feasibility and applicability of religion and media by further research. Support groups emerged an important facilitators, however there is a need to explore the existing support and make provisions to make that support more widely available. Forcing adolescents to disclose or

unnecessary disclosure on their behalf should be avoided and if possible their rights to disclose should be protected by guidelines or laws.

REFERENCES:

Abramowitz, S., Koenig, L. J., Chandwani, S., Orban, L., Stein, R., Lagrange, R., & Barnes, W. (2009). Characterizing social support: global and specific social support experiences of HIV-infected youth. *AIDS Patient Care and STDs*, *23*(5), 323–330. http://doi.org/10.1089/apc.2008.0194

Adejumo, A. O. (2011). Perceived HIV stigmatization, HIV/AIDS cognition and personality as correlates of HIV self-disclosure among people living with HIV in Ibadan, Nigeria. *Gender and Behaviour*, *9*(2), 3854–3869. http://doi.org/10.4314/gab.v9i2.72113

Attia, S., Egger, M., Müller, M., Zwahlen, M., & Low, N. (2009). Sexual transmission of HIV according to viral load and antiretroviral therapy: systematic review and meta-analysis. *AIDS (London, England)*, *23*(11), 1397–1404. http://doi.org/10.1097/QAD.0b013e32832b7dca

AVERT. (2012). HIV & AIDS in Zimbabwe. Retrieved August 8, 2015, from http://www.avert.org/hiv-aids-zimbabwe.htm

Bakeera-Kitaka, S., Nabukeera-Barungi, N., Nöstlinger, C., Addy, K., & Colebunders, R. (2008). Sexual risk reduction needs of adolescents living with HIV in a clinical care setting. *AIDS Care*, *20*(4), 426–433. http://doi.org/10.1080/09540120701867099

Batterham, P., Rice, E., & Rotheram-Borus, M. J. (2005). Predictors of serostatus disclosure to partners among young people living with HIV in the pre- and post-HAART eras. *AIDS and Behavior*, *9*(3), 281–287. http://doi.org/10.1007/s10461-005-9002-5

Benjamin James Saddock, Virginia Alcott Saddock. (2007). *KAPLAN AND SADOCK'S SYNOPSIS OF PSYCHIATRY. Behavior sciences/clinical psychiatry* (10th ed., Vol. 1).

Bicego G, & Rutstein S. (2003). Dimensions of the emerging orphan crisis in sub-Saharan Africa. - PubMed - NCBI. Retrieved July 30, 2015, from http://www.ncbi.nlm.nih.gov/pubmed/12600361

Birungi, H., Obare, F., Mugisha, J. F., Evelia, H., & Nyombi, J. (2009). Preventive service needs of young people perinatally infected with HIV in Uganda. *AIDS Care*, *21*(6), 725–731. http://doi.org/10.1080/09540120802511901

Burns, N., Grove, S. K., & Gray, J. (2011). *Understanding nursing research: building an evidence-based practice*. Maryland Heights, MO: Elsevier/Saunders.

Calabrese, S. K., Martin, S., Wolters, P. L., Toledo-Tamula, M. A., Brennan, T. L., & Wood, L. V. (2012). Diagnosis disclosure, medication hiding, and medical functioning among perinatally infected, HIV-positive children and adolescents. *AIDS Care*, *24*(9), 1092–1096. http://doi.org/10.1080/09540121.2012.699670

Campbell, C., Skovdal, M., Mupambireyi, Z., & Gregson, S. (2010). Exploring children's stigmatisation of AIDS-affected children in Zimbabwe through drawings and stories. *Social Science & Medicine*, *71*(5), 975–985. http://doi.org/10.1016/j.socscimed.2010.05.028

Cardoso, C. A. A., Pinto, J. A., Candiani, T. M. S., Carvalho, I. R. de, Linhares, R. M., & Goulart, E. M. A. (2012b). The impact of highly active antiretroviral therapy on the survival of vertically HIV-infected children and adolescents in Belo Horizonte, Brazil. *Memórias Do Instituto Oswaldo Cruz*, *107*(4), 532–538.

Carpenter, C., & Suto, M. (2008). *Qualitative research for occupational and physical therapists: a practical guide*. Oxford; Ames, Iowa: Blackwell Pub.

Castle, S. (2004). Rural children's attitudes to people with HIV/AIDS in Mali: the causes of stigma. *Culture, Health & Sexuality*, *6*(1), 1–18. http://doi.org/10.1080/13691050310001622460

Chao, L.-W., Gow, J., Akintola, G., & Pauly, M. (2010). HIV/AIDS Stigma Attitudes Among Educators in KwaZulu-Natal, South Africa. *Journal of School Health*, *80*(11), 561–569. http://doi.org/10.1111/j.1746-1561.2010.00542.x

Chenneville, T., Lynn, V., Peacock, B., Turner, D., & Marhefka, S. L. (2015). Disclosure of HIV Status Among Female Youth With HIV. *Ethics & Behavior*, *25*(4), 314–331. http://doi.org/10.1080/10508422.2014.934371

Choi, J. Y. (2014). HIV Stigmatization Harms Individuals and Public Health.

Cluver, L. D., Hodes, R. J., Toska, E., Kidia, K. K., Orkin, F. M., Sherr, L., & Meinck, F. (2015). "HIV is like a tsotsi. ARVs are your guns": associations between HIV-disclosure and adherence to antiretroviral treatment among adolescents in South Africa. *AIDS (London, England)*, *29 Suppl 1*, S57–65. http://doi.org/10.1097/QAD.0000000000000695

Creel, A., Rimal, R., Makandawire, G., & Brown, J. (2011, June). Effects of a mass media intervention on HIV-related stigma: "Radio Diaries" program in Malawi. - PubMed - NCBI. Retrieved July 30, 2015, from http://www.ncbi.nlm.nih.gov/pubmed/21393376

D'Angelo, L. J., Abdalian, S. E., Sarr, M., Hoffman, N., Belzer, M., & Adolescent Medicine HIV/AIDS Research Network. (2001). Disclosure of serostatus by HIV infected youth: the experience of the REACH study. Reaching for Excellence in Adolescent Care and Health. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine*, *29*(3 Suppl), 72–79.

Day, C., Ross, J., & Dolan, K. (2003). Hepatitis C-related discrimination among heroin users in Sydney: drug user or hepatitis C discrimination? *Drug and Alcohol Review*, *22*(3), 317–321. http://doi.org/10.1080/0959523031000154463

Deacon, H., & Stepheny, I. (2007). *HIV/AIDS, stigma and children - A literature review.* Cape Town.

Dempsey, A. G., MacDonell, K. E., King, S. N., & Lau, C.-Y. (2012). Patterns of Disclosure among Youth who are HIV Positive: A Multisite Study. *The Journal of Adolescent Health*, *50*(3), 315–317. http://doi.org/10.1016/j.jadohealth.2011.06.003

Di Risio, M., Ballantyne, P. J., Read, S. E., & Bendayan, R. (2011). "HIV isn't me…": HIV+ adolescents' experiences in a positive context of support and treatment. *AIDS Care*, *23*(6), 694–699. http://doi.org/10.1080/09540121.2010.532539

Erku, T. A., Megabiaw, B., & Wubshet, M. (2012). Predictors of HIV status disclosure to sexual partners among People living with HIV/AIDS in Ethiopia. *The Pan African Medical Journal*, *13*. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3567411/

Fair, C., & Albright, J. (2012). "Don't Tell Him You Have HIV Unless He's 'The One'": Romantic Relationships Among Adolescents and Young Adults with Perinatal HIV Infection. *AIDS Patient Care and STDs*, *26*(12), 746–754. http://doi.org/10.1089/apc.2012.0290

Fatti, G., Bock, P., Eley, B., Mothibi, E., & Grimwood, A. (2011). Temporal trends in baseline characteristics and treatment outcomes of children starting antiretroviral treatment: an analysis in four provinces in South Africa, 2004-2009. *Journal of Acquired Immune Deficiency Syndromes (1999)*, *58*(3), e60–67. http://doi.org/10.1097/QAI.0b013e3182303c7e

Forsberg, A. D., King, G., Delaronde, S. R., & Geary, M. K. (1996). Maintaining safer sex behaviours in HIV-infected adolescents with haemophilia. The Hemophilia Behavioral Evaluative Intervention Project Committee. - PubMed - NCBI. Retrieved July 13, 2015,

from http://www.ncbi.nlm.nih.gov/pubmed/?term=Maintaining+safer+sex+behaviours+in+HIV-infected+adolescents+with+haemophilia.

Greeff, M., Phetlhu R., Makoae LN., Dlamini PS., Holzemer WL., Naidoo JR., Kohi TW., Uys LR., Chirwa ML. Disclosure of HIV status: experiences and perceptions of persons living with HIV/AIDS and nurses involved in their care in Africa. Qual Health Res. 2008 Mar: 18 (3): 311-24.

Gale, K. N., Heath, G., Cameron, E., Rashid, S., & Redwood, S. Using the framework method for the analysis of frameowrk data in multi-disciplinary health research. BMC Medical Research Methodology, 13: 117 2013.

Geary, M. K., King, G., Forsberg, A. D., Delaronde, S. R., & Parsons, J. (1996). Issues of disclosure and condom use in adolescents with hemophilia and HIV. Hemophilia Behavioral Evaluative Intervention Project Staff. *Paediatric AIDS and HIV Infection*, *7*(6), 418–423.

Gerson, A. C., Joyner, M., Fosarelli, P., Butz, A., Wissow, L., Lee, S., Hutton, N. (2001). Disclosure of HIV diagnosis to children: when, where, why, and how. *Journal of Paediatric Health Care: Official Publication of National Association of Paediatric Nurse Associates & Practitioners*, *15*(4), 161–167. http://doi.org/10.1067/mph.2001.114835

Gillard, A., & Roark, M. (2012). Older Adolescents' Self-Determined Motivations to Disclose Their HIV Status. *Journal of Child and Family Studies*, *22*(5), 672–683. http://doi.org/10.1007/s10826-012-9620-2

Glynn, J. R., Caraël, M., Auvert, B., Kahindo, M., Chege, J., Musonda, R., … Study Group on the Heterogeneity of HIV Epidemics in African Cities. (2001). Why do young women have a much higher prevalence of HIV than young men? A study in Kisumu, Kenya and Ndola, Zambia. *AIDS (London, England)*, *15 Suppl 4*, S51–60.

Greco P, Pendley JS, Mcdonell K, & Reeves G. (2001, December). A peer group intervention for adolescents with type 1 diabetes and their best friends. - PubMed - NCBI. Retrieved July 31, 2015, from http://hinarilogin.research4life.org/uniquesigwww.ncbi.nlm.nih.gov/uniquesig0/pubmed/11700333

Hadjipateras, A. (2004). Unravelling the dynamics of HIV/AIDS- related stigma and discrimination. The role of community based research: Case studies of northern Uganda and Burundi. London: Agency for Co-operation and Research Development (ACORD).

Heisler, M. (2007). Overview of Peer Support Models to Improve Diabetes Self-Management and Clinical Outcomes. *Diabetes Spectrum*, *20*(4), 214–221. http://doi.org/10.2337/diaspect.20.4.214

Herek, G. M., Mitnick, L., Burris, S., Chesney, M., Devine, P., Fullilove, M. T., … Sweeney, T. (1998). Workshop report: AIDS and stigma: a conceptual framework and research agenda. *AIDS & Public Policy Journal*, *13*(1), 36–47.

Hodgson, I., Ross, J., Haamujompa, C., & Gitau-Mburu, D. (2012). Living as an adolescent with HIV in Zambia -- lived experiences, sexual health and reproductive needs. *AIDS Care*, *24*(10), 1204–1210. http://doi.org/10.1080/09540121.2012.658755

Hogwood, J., Campbell, T., & Butler, S. (2013). I wish I could tell you but I can't: adolescents with perinatally acquired HIV and their dilemmas around self-disclosure. *Clinical Child Psychology and Psychiatry*, *18*(1), 44–60. http://doi.org/10.1177/1359104511433195

Kidia, K. K., Mupambireyi, Z., Cluver, L., Ndhlovu, C. E., Borok, M., & Ferrand, R. A. (2014). HIV status disclosure to perinatally-infected adolescents in Zimbabwe: a qualitative study of adolescent and healthcare worker perspectives. *PloS One*, *9*(1), e87322. http://doi.org/10.1371/journal.pone.0087322

Klepp, K. I., Ndeki, S. S., Seha, A. M., Hannan, P., Lyimo, B. A., Msuya, M. H., Schreiner, A. (1994). AIDS education for primary school children in Tanzania: an evaluation study. *AIDS (London, England)*, *8*(8), 1157–1162.

Krauss, B. J., Letteney, S., Baets, A. J. D., Baggaley, R., & Okero, F. A. (2013). Disclosure of HIV status to HIV-positive children 12 and under: A systematic cross-national review of implications for health and well-being. *Vulnerable Children and Youth Studies*, *8*(2), 99–119. http://doi.org/10.1080/17450128.2012.750774

Lam, P. K., Naar-King, S., &Wright, K. (2007). Social support and disclosure as predictors of mental health in HIV-positive youth. *AIDS Patient Care and STDs*, *21*(1), 20–29. http://doi.org/10.1089/apc.2006.005

Lee, B., & Oberdorfer, P. (2009). Risk-taking behaviors among vertically HIV-infected adolescents in northern Thailand. *Journal of the International Association of Physicians*

in AIDS Care (Chicago, Ill.: 2002), *8*(4), 221–228. http://doi.org/10.1177/1545109709341082

Lee, R. (2010). *The SuperStress Solution.* Retrieved from http://www.penguinrandomhouse.com/books/99363/the-superstress-solution-by-roberta-lee-md/

Leonard, A. D., Markham, C. M., Bui, T., Shegog, R., & Paul, M. E. (2010). Lowering the risk of secondary HIV transmission: insights from HIV-positive youth and health care providers. *Perspectives on Sexual and Reproductive Health*, *42*(2), 110–116. http://doi.org/10.1363/4211010

Lesch, A., Swartz, L., Kagee, A., Moodley, K., Kafaar, Z., Myer, L., & Cotton, M. (2007). Paediatric HIV/AIDS disclosure: towards a developmental and process-oriented approach. *AIDS Care*, *19*(6), 811–816. http://doi.org/10.1080/09540120601129301

Lowenthal, E. D., Bakeera-Kitaka, S., Marukutira, T., Chapman, J., Goldrath, K., & Ferrand, R. A. (2014). Perinatally acquired HIV infection in adolescents from sub-Saharan Africa: a review of emerging challenges. *The Lancet Infectious Diseases*, *14*(7), 627–639. http://doi.org/10.1016/S1473-3099(13)70363-3

Mayfield A. E., Rice, E., Flannery, D., Rotheram-Borus, M. J.. HIV disclosure among adults living with HIV. ALDS Care. 2008 Jan; 20(1): 80-92.

Mburu, G., Hodgson, I., Kalibala, S., Haamujompa, C., Cataldo, F., Lowenthal, E. D., & Ross, D. (2014). Adolescent HIV disclosure in Zambia: barriers, facilitators and outcomes. *Journal of the International AIDS Society*, *17*(1). http://doi.org/10.7448/IAS.17.1.18866

Medley A., Garcia-Moreno C., McGill S., Maman S. Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: implications for prevention of mother-to-child transmission programmes. Bull World Health Organ. 2004 Apr; 82(4): 299-307.

Menon, A., Glazebrook, C., Campain, N., & Ngoma, M. (2007). Mental health and disclosure of HIV status in Zambian adolescents with HIV infection: implications for peer-support programs. *Journal of Acquired Immune Deficiency Syndromes (1999)*, *46*(3), 349–354. http://doi.org/10.1097/QAI.0b013e3181565df0

Michaud, P.-A., Suris, J.-C., Thomas, L. R., Kahlert, C., Rudin, C., & Cheseaux, J.-J. (2009). To say or not to say: a qualitative study on the disclosure of their condition by human

immunodeficiency virus-positive adolescents. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine*, *44*(4), 356–362. http://doi.org/10.1016/j.jadohealth.2008.08.004

Mupambireyi, Z., Bernays, S., Bwakura-Dangarembizi, M., & Cowan, F. M. (2014). "I don't feel shy because I will be among others who are just like me…": The role of support groups for children

perinatally infected with HIV in Zimbabwe. *Children and Youth Services Review*, *45*, 106–113. http://doi.org/10.1016/j.childyouth.2014.03.026

N-vivo 10. QSR international, 2012).

O'Brien, M. E., Richardson-Alston, G., Ayoub, M., Magnus, M., Peterman, T. A., & Kissinger, P. (2003). Prevalence and correlates of HIV serostatus disclosure. *Sexually Transmitted Diseases*, *30*(9), 731–735. http://doi.org/10.1097/01.OLQ.0000079049.73800.C2

O'Leary A, Kennedy M, & Galavotti C. (2007, January). Association between exposure to an HIV story line in The Bold and the Beautiful and HIV-related stigma in Botswana. - PubMed - NCBI. Retrieved July 30, 2015, from http://www.ncbi.nlm.nih.gov/pubmed/17563275

Ortblad, K. F., Lozano, R., & Murray, C. J. L. (2013). The burden of HIV: insights from the Global Burden of Disease Study 2010. *AIDS (London, England)*, *27*(13), 2003–2017. http://doi.org/10.1097/QAD.0b013e328362ba67

Patel, R., Ratner, J., Gore-Felton, C., Kadzirange, G., Woelk, G., & Katzenstein, D. (2012). HIV disclosure patterns, predictors, and psychosocial correlates among HIV positive women in Zimbabwe. *AIDS Care*, *24*(3), 358–368. http://doi.org/10.1080/09540121.2011.608786

Paudel, V., & Baral, K. P. (2015). Women living with HIV/AIDS (WLHA), battling stigma, discrimination and denial and the role of support groups as a coping strategy: a review of literature. *Reproductive Health*, *12*. http://doi.org/10.1186/s12978-015-0032-9

Pesani, E. (1999). *Acting early to prevent AIDS: The case of Senegal*. UNAIDS.

Petersen, I., Bhana, A., Myeza, N., Alicea, S., John, S., Holst, H., Mckay, M., Mellins, C. Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: a qualitative investigation. AIDS Care. 2010 Aug; 22(8): 970-8.

Pinkerton, S. D., & Galletly, C. L. (2007). Reducing HIV transmission risk by increasing serostatus disclosure: a mathematical modelling analysis. *AIDS and Behavior*, *11*(5), 698–705. http://doi.org/10.1007/s10461-006-9187-2

Pinzón-Iregui, M. C., Beck-Sagué, C. M., & Malow, R. M. (2013). Disclosure of their HIV status to infected children: a review of the literature. *Journal of Tropical Paediatrics*, *59*(2), 84–89. http://doi.org/10.1093/tropej/fms052

Protudjer, J. L. P., Kozyrskyj, A. L., Becker, A. B., & Marchessault, G. (2009). Normalization Strategies of Children With Asthma. *Qualitative Health Research*, *19*(1), 94–104. http://doi.org/10.1177/1049732308327348

Qin, J., Yang, T., Kong, F., Wei, J., & Shan, X. (2013). Students and their parental attitudes toward the education of children affected by HIV/AIDS: a cross-sectional study in AIDS prevalent rural areas, China. *Australian and New Zealand Journal of Public Health*, *37*(1), 52–57. http://doi.org/10.1111/1753-6405.12010

Rabia Khan. (2013). *Prevalence and factors associated with depression in HIV infected adolescents attending HIV care clinics at two tertiary hospitals in Harare, Zimbabwe.* University of Zimbabwe, Harare.

Rice, E., Batterham, P., & Rotheram-Borus, M. J. (2006). Unprotected sex among youth living with HIV before and after the advent of highly active antiretroviral therapy. *Perspectives on Sexual and Reproductive Health*, *38*(3), 162–167. http://doi.org/10.1363/psrh.38.162.06

Robinson, C. A. (1993). Managing Life with a Chronic Condition: The Story of Normalization. *Qualitative Health Research*, *3*(1), 6–28. http://doi.org/10.1177/104973239300300102

Rongkavilit, C., Wright, K., Chen, X., Naar-King, S., Chuenyam, T., & Phanuphak, P. (2010). HIV stigma, disclosure and psychosocial distress among Thai youth living with HIV. *International Journal of STD & AIDS*, *21*(2), 126–132. http://doi.org/10.1258/ijsa.2009.008488

Roux, P., Fugon, L., Michel, L., Lert, F., Obadia, Y., Spire, B., & Carrieri, M. P. (2011). Determinants of benzodiazepine use in a representative population of HIV-infected individuals: the role of HIV status disclosure (ANRS-EN12-VESPA study). *AIDS Care*, *23*(9), 1163–1170. http://doi.org/10.1080/09540121.2011.555738

Saddock, B. J., & Saddock, V. A. (2007). *Kaplan and Saddock's synopsis of Psychiatry.* (10th ed., Vol. 1).

Shacham, E., Small, E., Onen, N., Stamm, K., & Overton, E. T. (2012). Serostatus disclosure among adults with HIV in the era of HIV therapy. *AIDS Patient Care and STDs*, *26*(1), 29–35. http://doi.org/10.1089/apc.2011.0183

Siegel, K., & Lekas, H.-M. (2002). AIDS as a chronic illness: psychosocial implications. *AIDS (London, England)*, *16 Suppl 4*, S69–76.

Simbayi, L., Kalichman, S., Strebel, A., & Mqeketo, A. (2007, May). Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa. - PubMed - NCBI. Retrieved July 30, 2015, from http://hinarilogin.research4life.org/uniquesigwww.ncbi.nlm.nih.gov/uniquesig0/pubmed/17337318

Siu, G. E., Bakeera-Kitaka, S., Kennedy, C. E., Dhabangi, A., & Kambugu, A. (2012a). HIV serostatus disclosure and lived experiences of adolescents at the Transition Clinic of the Infectious Diseases Clinic in Kampala, Uganda: a qualitative study. *AIDS Care*, *24*(5), 609. http://doi.org/10.1080/09540121.2011.630346

Siu, G. E., Bakeera-Kitaka, S., Kennedy, C. E., Dhabangi, A., & Kambugu, A. (2012). HIV serostatus disclosure and lived experiences of adolescents at the Transition Clinic of the Infectious Diseases Clinic in Kampala, Uganda: A qualitative study. *AIDS Care*, *24*(5), 606–611. http://doi.org/10.1080/09540121.2011.630346

Smith, M. (2013). Anti-stigma campaigns: time to change. *The British Journal of Psychiatry*, *202*(s55), s49–s50. http://doi.org/10.1192/bjp.bp.113.126813

Stirratt, M. J., Remien, R. H., Smith, A., Copeland, O. Q., Dolezal, C., Krieger, D., & SMART Couples Study Team. (2006). The role of HIV serostatus disclosure in antiretroviral medication adherence. *AIDS and Behavior*, *10*(5), 483–493. http://doi.org/10.1007/s10461-006-9106-6

Sullivan C. A., Male self-disclosure of HIV-positive serostatus to sex partners: a review of the literature. J Assoc Nurses AIDS Care. 2005Nov-Dec; 16(6): 33-47.

Tam, M., Amzel, A., Phelps B.R. Disclosure of HIV serostatus among pregnant and postpartum women in Sub-Saharan Africa: a systematic review. AIDS Care. 2015; 27 (4): 436-50.

Thoth, C. A., Tucker, C., Leahy, M., & Stewart, S. M. (2014). Self-disclosure of serostatus by youth who are HIV-positive: a review. *Journal of Behavioral Medicine*, *37*(2), 276–288. http://doi.org/10.1007/s10865-012-9485-2

UNAIDS. (2012a). *A progress report on the Global Plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive*.

UNAIDS. (2012b). *UNAIDS youth brochure.* (pp. 3–4).

UNAIDS. (2013). *Global Report. UNAIDS report on global AIDS epidemic 2013.*

UNAIDS. (2014). *Global AIDS Response Country Progress Report , Zimbabwe 2014.*

UNAIDS. (2000). *Opening up HIV/AIDS epidemic , Guidance on encouraging beneficial disclosure, ethical partner counselling & appropriate use of HIV case reporting*.

UNICEF. (2013). *UNICEF Data: Monitoring the Situation of Children and Women*.

Valle, A., Treviño, A. C., Zambrano, F. F., Urriola, K. E., Sánchez, L. A., & Elizondo, J. E. (2015). Perceived HIV-Associated Stigma among HIV-Seropositive Men: Psychometric Study of HIV Stigma Scale. *Frontiers in Public Health*, *3*. http://doi.org/10.3389/fpubh.2015.00171

van Dijk, J. H., Sutcliffe, C. G., Munsanje, B., Sinywimaanzi, P., Hamangaba, F., Thuma, P. E., & Moss, W. J. (2011). HIV-infected children in rural Zambia achieve good immunologic and virologic outcomes two years after initiating antiretroviral therapy. *PloS One*, *6*(4), e19006. http://doi.org/10.1371/journal.pone.0019006

Vreeman, R. C., Gramelspacher, A. M., Gisore, P. O., Scanlon, M. L., & Nyandiko, W. M. (2013). Disclosure of HIV status to children in resource-limited settings: a systematic review. *Journal of the International AIDS Society*, *16*, 18466.

Vyavaharkar, M., Moneyham, L., Corwin, S., Tavakoli, A., Saunders, R., & Annang, L. (2011). HIV-disclosure, social support, and depression among HIV-infected African American women living in the rural south-eastern United States. *AIDS Education and Prevention: Official Publication of the International Society for AIDS Education*, *23*(1), 78–90. http://doi.org/10.1521/aeap.2011.23.1.78

WHO. (2011). *Guideline on HIV disclosure counselling for children up to 12 years of age*.

WHO. (2013, November). WHO | HIV and adolescents: Guidance for HIV testing and counselling and care for adolescents living with HIV. Retrieved June 28, 2015, from http://www.who.int/hiv/pub/guidelines/adolescents/en/

Wiener, L. S., & Battles, H. B. (2006). Untangling the web: A close look at diagnosis disclosure among HIV-infected adolescents. *Journal of Adolescent Health*, *38*(3), 307–309. http://doi.org/10.1016/j.jadohealth.2005.03.024

World Health Organization. (2001). *Innovative care for chronic conditions. Non-communicable Diseases and Mental Health Meeting Report.* (pp. 1–35).

World Health Organization. (2013, November). HIV AND ADOLESCENTS: HIV TESTING AND COUNSELLING, TREATMENT AND CARE FOR ADOLESCENTS LIVING WITH HIV NOVEMBER 2013 POLICY BRIEF SUMMARY OF KEY FEATURES AND RECOMMENDATIONS.

APPENDIX I

Interview guide

This study aims at looking at the perspectives of HIV infected adolescents towards disclosure of their HIV status to others. We are interested in knowing the patterns, experiences, facilitators and barriers to disclosing your HIV status to others.

We value each one of your thoughts and opinions. Please remember that there are no right or wrong answers or views. Please feel free to discuss just what you think. If there are issues that you really do not want to discuss you are free to not do so. Everything that is discussed in the interview is confidential. This interview should last for about 45 minute's to1 hour.

If you agree, I would like to record our discussion in writing and on tape. But these will not be shared with anyone else. I will be writing about your responses in a report but no identifying information such as names will be included in the reports.

Thank you for helping us with this study.

Participant No	
Date of Interview	
Interviewer Name/s	
Interview Start time	
Interview end time	

Key demographics:

1. Date Of birth: DD/MM/YY
2. Gender:
3. Parental status:
    a. Both parents alive
    b. Only father alive

c. Only mother alive
d. Both parents dead

4. Do you know the HIV status of your parents?
5. Does you have siblings? Do you know the HIV status of your siblings?
6. Who do you stay with?
    a. With father
    b. With mother
    c. With grandparents
    d. Other relatives
    e. Non- relatives / alone
7. Current school attendance yes/ No
8. Are you taking ARV's? Yes? No
9. Do you attend a support group? Yes/no.

9Ext. If yes, how frequently do you attend the support group?

10. Please could you tell me about what you know about how people get HIV?

Prompts:

i. What do you mean by that? (For ambiguous responses like born with it)
ii. Where did you learn about these different ways?
iii. Can you tell us about your experience of getting HIV?

11. How did you feel when you came to know about HIV? How long ago was that? How do you feel now? Can you look at the different expressions and try and identify which expression matches your feelings? Have you got any question regarding HIV or how HIV status was disclosed to you?
12. Please could you tell me how you feel about disclosing your status to others?

Prompts:

i. Overall impression about Disclosure to others: yes / no

ii. If yes, when you think is the best time to disclose your status to others?
iii. Are there particular people you think it is important to disclose to?
iv. What might make it difficult to disclose to others?
v. What might make it easy for you to disclosure to others?

13. Could you tell me about your own experience about disclosing your status to other people?

Prompts:

i. At the present time, who knows that you are HIV positive?
ii. Did you disclose your status to others?
iii. If you haven't yourself has anyone else has disclosed your status to others without your permission.
iv. When did this happen?
v. Can you take me through the process? To whom did u disclose and under what circumstances?
vi. What was the process leading up to the time you disclosed? Did you just tell him/her straight away?
vii. How was your experience like? How did the other person respond?
viii. How do you feel about this past experience of disclosing to others?

14. Could you please tell me what your family, counsellors and support group say about disclosing to others?

Prompts:

i. Family assistance: talking about the process, whether to disclose to others or not? Who to disclose to? Why and why not to disclose?
ii. Health care worker: talking about the process, whether to disclose to others or not? Who to disclose to? Why and why not to disclose?
iii. What do you think about the role of support groups?

15. If your friend asked you whether he/she should disclose to someone else, what will you say to him/her

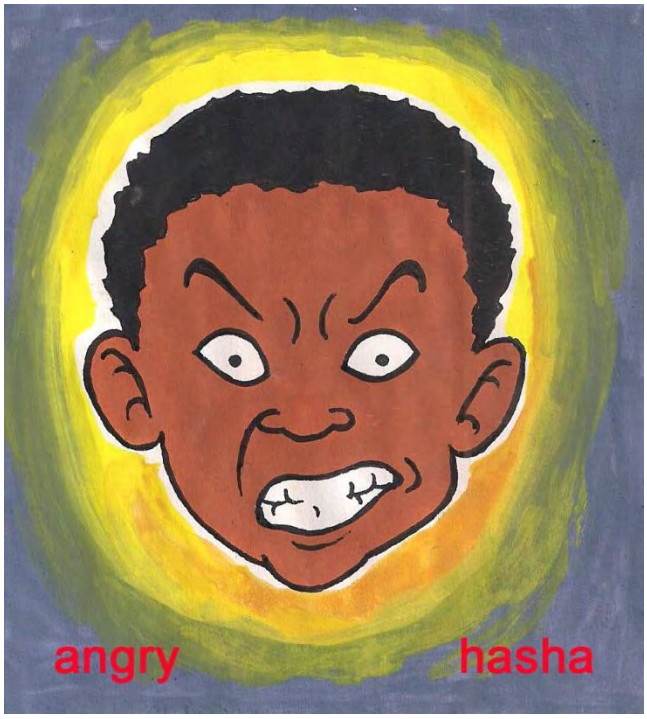
Prompts:

i. To disclose to others or not?
ii. When to disclose?
iii. How to disclose?

16. Health workers want to learn how they can help adolescents with this issue of disclosure. What would your message be to them?

I want to thank you for sharing your experiences and feelings with me. This has helped me to have a better understanding of the process of disclosure. I hope you also had a pleasant

Emotion map: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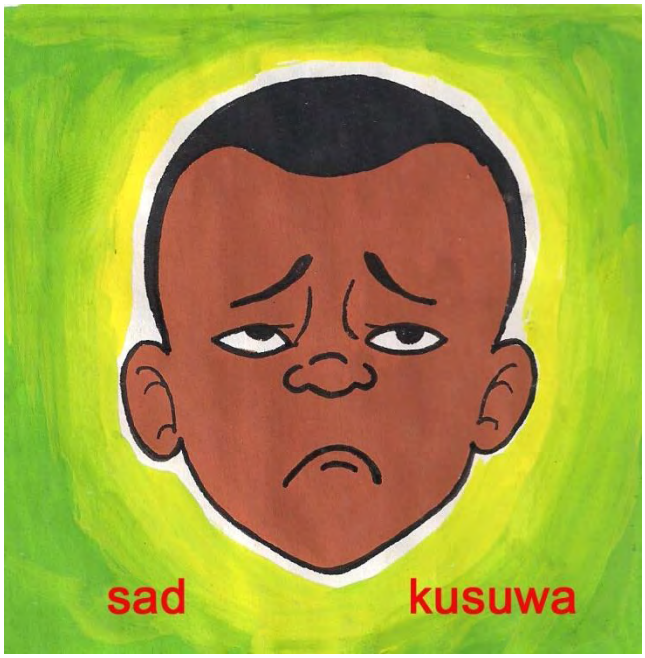
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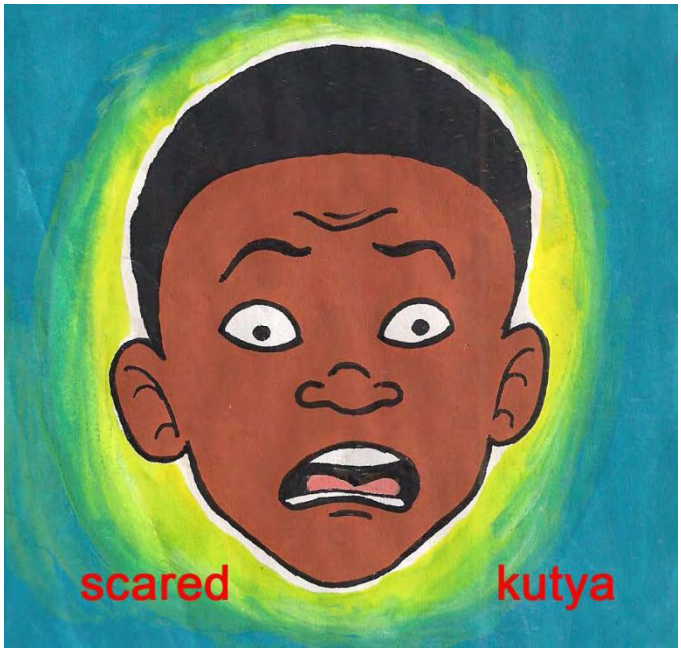
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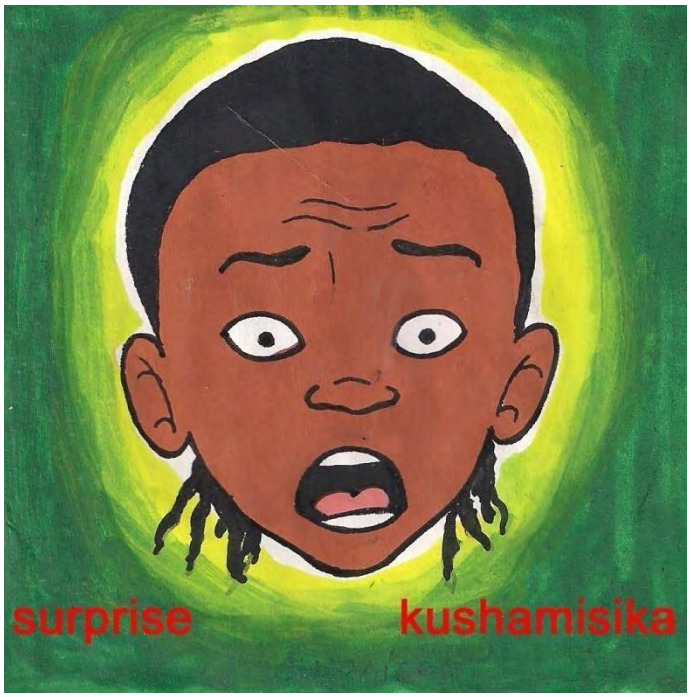
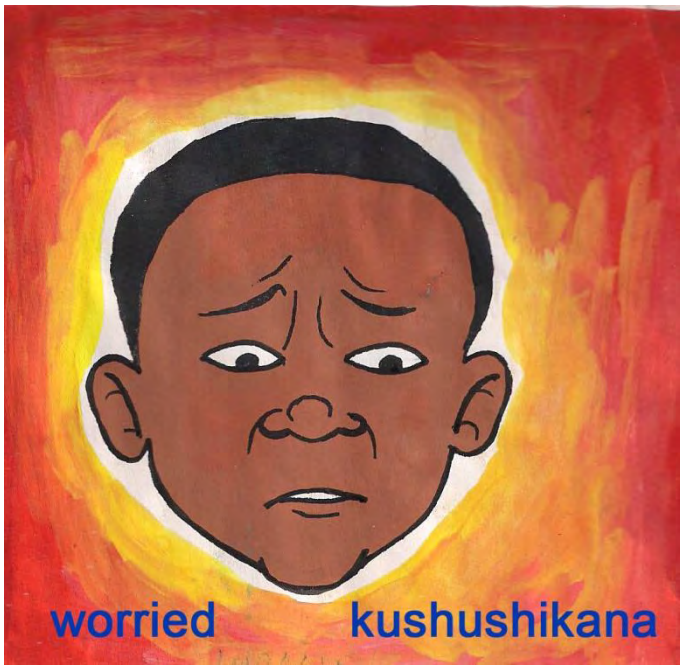

surprise
kushamisika


tired
kuneta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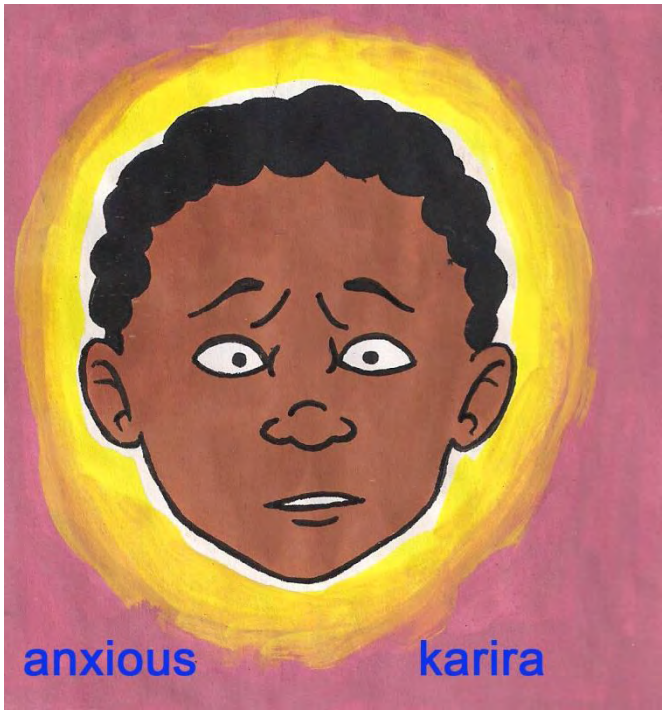
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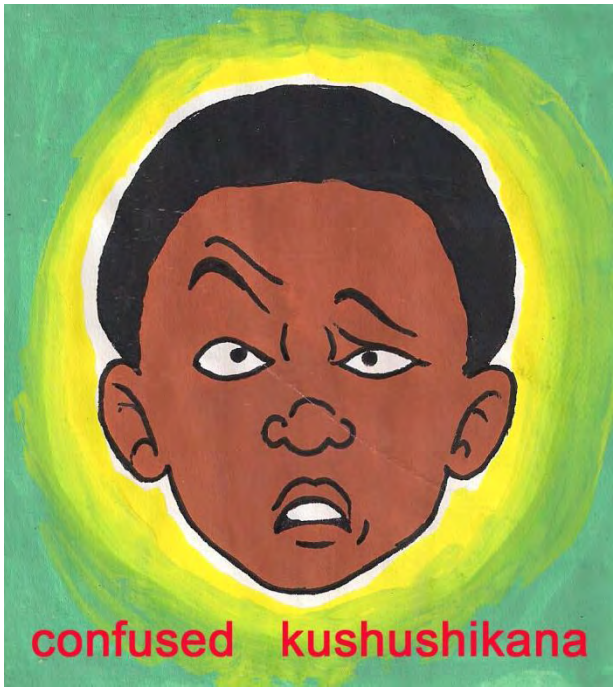
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content
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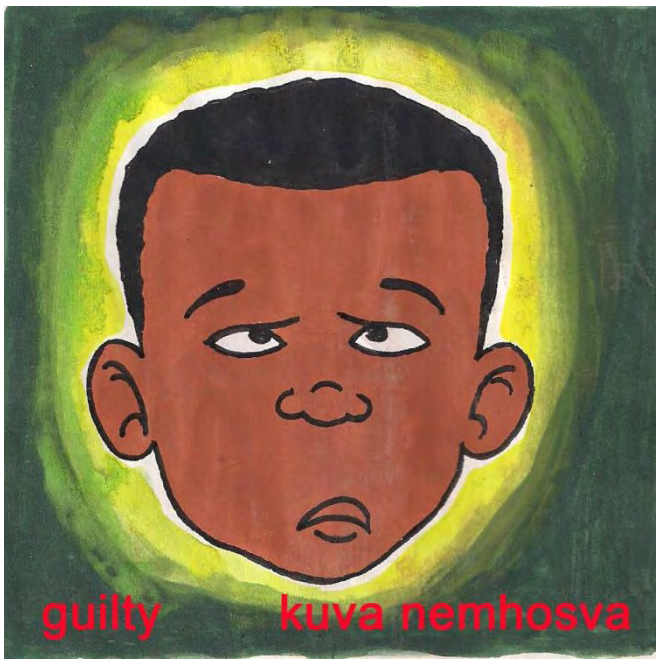
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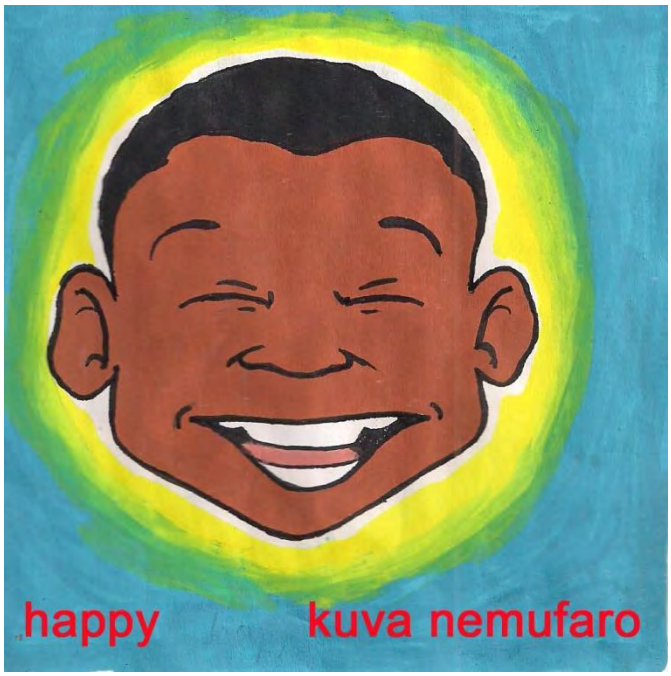
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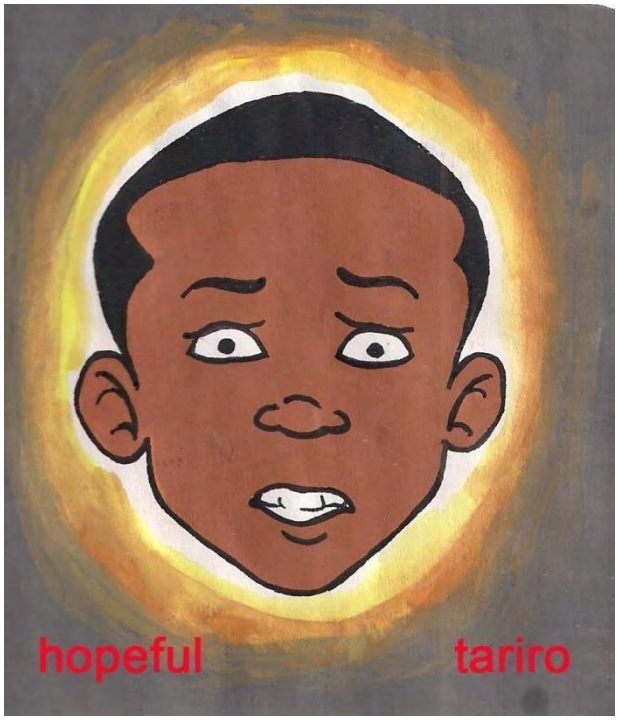
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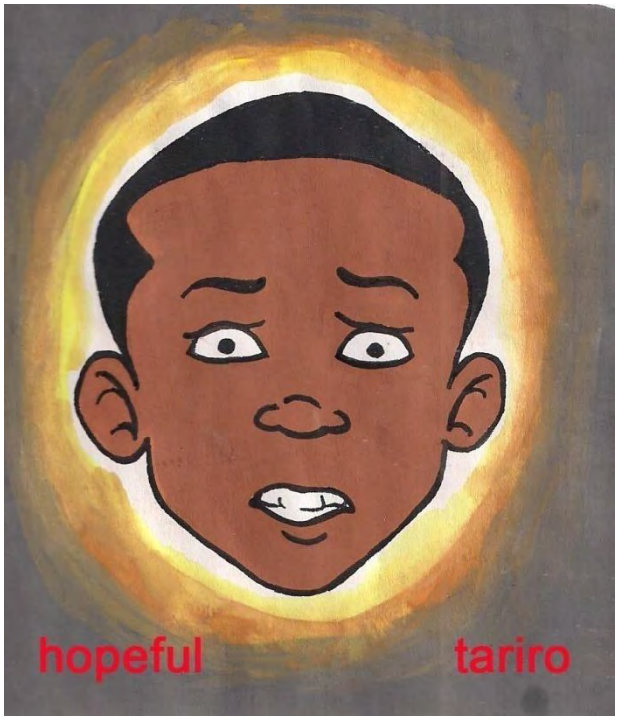
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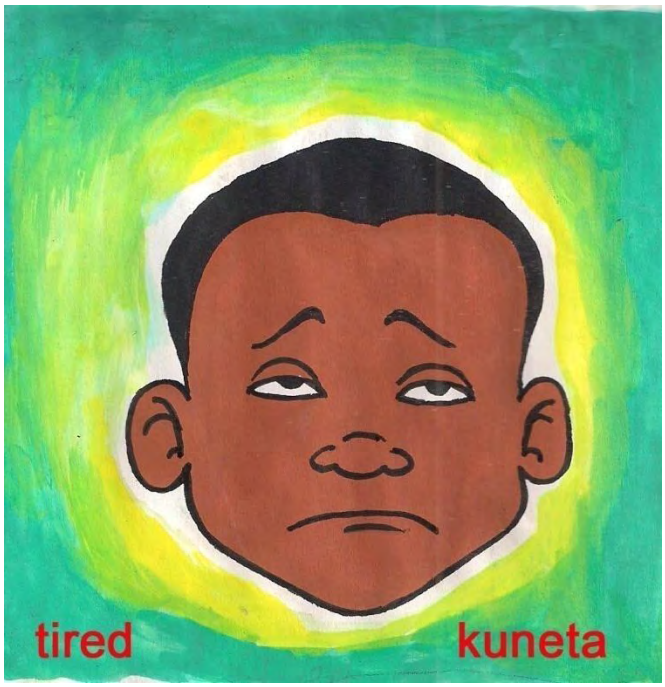
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APPENDIX II:

Information Sheet:

TITLE: Perspectives on disclosure of HIV status to others among 12-19yrs old HIV infected adolescents attending HIV care clinic at a tertiary hospital in Harare, Zimbabwe… a qualitative study.

Investigator: Dr. Rabia Khan

Work Address: Psychiatric unit, Harare central Hospital

Cell: - + 263772419275

Email: drrabiakn@yoafrica.com

Funding Organization : AFFIRM

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the principal investigator if you have any questions about any part of this project that you do not fully understand. It is very important that you fully understand what this research entails and how you could be involved. Also, your participation is entirely voluntary and you are free to decline to participate. If you decide not to participate, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part. This study has been approved by the Joint Ethical Research Committee of Harare Central Hospital, Medical and Research Council of Zimbabwe and Human Research Ethic Committee of the University of Cape Town.

1. **What is this research study all about?** The aim of this study is to understand about the perspectives of HIV infected adolescent about their HIV status disclosure to others. The research team will conduct interview with each participant. During the interviews you, as a participant will be asked to explain about your views, experiences and possible factors which can make it easy or difficult for you to disclose your HIV status to others. Interviews will be facilitated by pictures to help them express their emotions better.

Why have you been invited to participate? You have been invited to participate, because you are attending the HIV care clinic at Harare central hospital.

What will your responsibilities be? As a participant you are requested to share your experiences according to the questions that I will, ask as openly and freely as you possibly can.

2. **Will you benefit from taking part in this research?** As a participant you stand to benefit from a clearer understanding of your own experiences in the disclosure process.
3. **Are there in risks involved in your taking part in this research?** It is possible that you might experience feelings of discomfort when talking about your ideas and experiences. However, I will ensure that a professional person is available to talk to you about these feelings, should you wish to do so.
4. **If you do not agree to take part, what alternatives do you have?** If you do not agree to take part it will have no influence on the treatment that you receive at HIV care clinic at Harare Central Hospital.
5. **Who will have access to your medical records?** I do not need any access to your medical records to conduct this research.
6. **Will you be paid to take part in this study and are there any costs involved?** No, you will not be paid to take part in the study but your transport costs will be covered if you come back specifically for the study purposes. There will be no costs involved for you, if you do take part.
7. **Is there anything else that you should know or do?** You should inform your physician in the project that you are taking part in a research study. You can contact Dr. Katherine Sorsdahl at telephone number0027 21 65065675 or on her email address Katherine.sorsdahl@uct.ac.zaif you have any further queries or encounter any problems. You can contact the Medical and Research council of Zimbabwe on04-791792 or 04-79119if you have any concerns or complaints that have not been adequately addressed by the researcher. You will receive a copy of this information and consent form for your own records.

Participant consent form

By signing below, I, _____, agree to take part in a research study entitled, Perspectives on disclosure of HIV status to others among 12-19yrs old HIV infected adolescents attending HIV care clinic at a tertiary hospital in Harare, Zimbabwe… a qualitative study

I declare that:

 I have read or the researcher read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

 I have had a chance to ask questions and all my questions have been adequately answered.

 I understand that taking part in this study is voluntary and I have not been rushed to take part.

 I may choose to leave the study at any time and will not be penalized or prejudiced in any way.

I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at _____ on_____ 2014.

Signature of participant (agreeing to participate) _____

Signature of participant (agreeing to interview being audio recorded)_____

Signature of witness _____

Declaration by investigator

I, Dr Rabia Khan, declare that:

 I explained the information in this document to _____.

 I encouraged him/her to ask questions and took adequate time to answer them.

I am satisfied that he/she adequately understands all aspects of the research, as discussed above

 I did/did not use an interpreter.

Sign Signed at _____ on _____2014.

Signature of investigator ----------

Signature of witness ----------

APPENDIX III:

Parental Consent form

Perspectives on disclosure of HIV status to others among 12-19yrs old HIV infected adolescents attending HIV care clinic at a tertiary hospital in Harare, Zimbabwe… a qualitative study

Investigator: Dr. Rabia Khan (Medical doctor)

Phone no: 0772419275

Email address: drrabiakn@yoafrica.com

Supervisor 1: Dr. Katherine Sorsdahl (Department of Psychiatry and Mental Health, University of Cape Town)

Phone no: 0027 21 6506567

Supervisor 2: Zivai Mupambireyi (Research Manager -Adolescents group of studies-CeSHHAR Zimbabwe)

Phone no: 00263 77508 0884

What you should know about this research study:

We give you this consent form so that you may read about why this study is being done, what could be the possible problems and benefits of this research study.

Patients are usually treated with the best possible treatment with the aim of helping them. Research helps to get more information that may help future patients.

We cannot promise that this research will benefit your child. Just like usual treatment, this study can have small problems.

You can refuse to allow your child to take part or allow now and refuse later.

Your decision to allow your child to take part is totally your choice. Whatever you decide it will not affect your child's treatment in this clinic. Please read through this consent form carefully. Ask any questions before you make a decision.

Purpose

You are being asked to allow your child to take part in this study among 12-19 years old HIV positive patients who are attending the OI clinic (opportunistic infection clinic) of this hospital. Your child will be asked about what are their experiences and what they feel about telling other people about they being HIV positive.

This study is being done as we want to know what HIV positive adolescents (12-19yrs) think about telling others about their HIV. They will be asked about what they think about how to tell others about their HIV. They will be asked about how they have told others about their HIV and what helped them or caused problems for them while telling others. They will be shown different pictures to help them to talk about their feeling like sad, guilty or happy. This information will help health workers (doctors, nurses, counsellors)to see the importance of what adolescents (12-19yrs) themselves think about telling others about their HIV. Your child is selected to take part in this study simply because he/she is coming to this clinic. We will talk to 15-20 patients who will come to this clinic during the months of July to November 2014.

Procedures and duration

If you decide to allow your child to take part in this study, then we will ask him/her some questions relating to his/her family, the medicines he/she is taking and telling others about their HIV. Some of these questions are usually asked by their doctors or nurses. However in this study, we will talk to them in detail about telling others about their HIV. All the interviews will be taped to keep the record of our talk. I hope that he/she will try and give honest answers to the questions. The whole talk will take 45minutes to 1 hour of his/her time. They might be asked to come back for a second talk on another date.

Risks and discomforts

Participants might feel some stress after the talk. If we find them stressed, we will send them to get help.

Benefits and/or compensation

We cannot and do not promise that you or your child will benefit directly from the study. However the results of this study might help the clinic staff to give adolescents (12-19 years old)the support they need to help them tell others about their HIV.As this study will be done during one of your child's usual visit to the clinic so we will not pay him/her anything for taking part in this study. But if asked to come back for the purpose of the study we will pay you and your child for the transport (depending on how much it costs to travel to and from the hospital). For your child's time for taking part in this study, they will be thanked and offered a drink and something to eat.

Alternative procedures or treatments

None

Confidentiality

We will make sure that your information will not be shared with anyone else except the study team. We will talk to you in a private room so that no one else can hear our talk. All the forms and tapes will be stored in a locked cupboard in the Psychiatry Department of the University of Zimbabwe. Keys will be kept by the researcher only. All this information will be stored in a computer. Password will be known by the main researcher only. All this information will be kept for 3 years after publishing this study.

Additional costs

None are expected.

In the event of an injury

None is expected.

Voluntary participation-

Your child will only take part in this study if you and your child are willing to take part. Your child's doctor or nurse will not know that you have been asked to take part in the study. So if you agree or refuse to take part in the study, your child's doctor or nurse will not know about this and

it will not affect their treatment in this clinic. You can refuse to take part at any time before and during the talk and it will not cause any problem for you or your child.

Any questions you want to ask

Before you sign this form, please ask any questions about this study that you don't understand. You can take as long as you want to decide.

Authorization

You are making a decision whether or not to allow your child to take part in this study. Your signature indicates that you have read and understood the information provided above, have had all your questions answered and decided to allow your child to take part in this study.

_____

_____

Name of parent or guardian of the Participant (please print)

Date_____

_____ _____

Signature of parent or guardian of the participant (agreement for the child to participate in the study)

_____

Signature of parent or guardian of the participant (agreement for the interview to be Audio-recorded) _____

Signature of Research staff _____

YOU WILL BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP

If you have any more questions about this study or consent form which are not answered by the researcher, including questions about the study, your child's rights as a research participant or research related injuries, or if you feel that your child has been treated unfairly and would like to

talk to someone other than a member of the research team, please feel free to contact the Medical Research Council of Zimbabwe on telephone : 04-791792 or 04-791193 and Head of Paediatric Department, Dr. Louisa Chikara on telephone : 04 666519.

APPENDIX IV:

Assent form (English)

Perspectives on disclosure of HIV status to others among 12-19yrs old HIV infected adolescents attending HIV care clinic at a tertiary hospital in Harare, Zimbabwe… a qualitative study

Principal Investigator: Dr. Rabia Khan (Medical doctor)

Phone no: 0772419275

Email drrabiakn@yoafrica.com

Supervisor1: Dr. Katherine Sorsdahl (Department of Psychiatry and Mental Health, University of Cape Town)

Phone no: 0027 21 65065675

Supervisor 2: Zivai Mupambireyi (Research Manager -Adolescents group of studies-CeSHHAR Zimbabwe)

Phone no: 00263 77508 0884

What you should know about this research study:

We give you this consent form so that you may read about why this study is being done, what could be the possible problems and benefits of this research study.

Patients are usually treated with the best possible treatment with the aim of helping them. Research helps to get more information that may help future patients.

We cannot promise that this research will benefit you . Just like usual treatment, this study can have small problems.

You can refuse to take part or allow now and refuse later.

Your decision to take part in this study is totally your choice. Whatever you decide it will not affect your treatment in this clinic. Please read through this consent form carefully. Ask any questions before you make a decision.

Purpose

You are being asked to take part in this study among 12-19 years old HIV positive patients who are attending the OI clinic (opportunistic infection clinic) of this hospital. They will be asked about what are their experiences and what they feel about telling other people about they being HIV positive.

This study is being done as we want to know what HIV positive adolescents (12-19years) think about telling others about their HIV. They will be asked about what they think about how to tell others about their HIV. They will be asked about how they have told others about their HIV and what helped them or caused problems for them while telling others. They will be shown different pictures to help them to talk about their feeling like sad, guilty or happy. This information will help health workers (doctors, nurses, counsellors)to see the importance of what adolescents (12-19years) themselves think about telling others about their HIV. You are selected to take part in this study simply because you are coming to this clinic. We will talk to 15-20 patients who will come to this clinic during the months of July to November2014.

Procedures and duration

If you decide to take part in this study, then we will ask you some questions relating to your family, the medicines you are taking and what do you think about telling others about their HIV. Some of these questions are usually asked by your doctors or nurses. However in this study, we will talk to you in detail about telling others about your HIV. All the interviews will be taped to keep the record of our talk. I hope that you will try and give honest answers to the questions. The whole talk will take 45minutes to 1 hour of your time. You might be asked to come back for a second talk on another date.

Risks and discomforts

Participants might feel some stress after the talk. If we find them stressed, we will send them to get help.

Benefits and/or compensation

We cannot and do not promise that you will benefit directly from the study. However the results of this study might help the clinic staff to give adolescents (12-19years old) the support they need to help them tell others about their HIV.As this study will be done during one of your usual visit to the clinic so we will not pay you for taking part in this study. But if asked to come back for the purpose of the study we will pay you for the transport (depending on how much it costs to travel to and from the hospital). For your time for taking part in this study, you will be thanked and offered a drink and something to eat.

Alternative procedures or treatments

None

Confidentiality

We will make sure that your information will not be shared with anyone else except the study team. We will talk to you in a private room so that no one else can hear our talk. All the forms and tapes will be stored in a locked cupboard in the Psychiatry Department of the University of Zimbabwe. Keys will be kept by the researcher only. All this information will be stored in a computer. Password will be known by the main researcher only. All this information will be kept for 3 years after publishing this study.

Additional costs

None are expected.

In the event of an injury

None is expected.

Voluntary participation-

You will only take part in this study if you are willing to take part. Your doctor or nurse will not know that you have been asked to take part in this study. So if you agree or refuse to take part in

the study, your doctor or nurse will not know about this and it will not affect your treatment in this clinic. You can refuse to take part at any time before and during the talk and it will not cause any problem for you.

Any questions you want to ask

Before you sign this form, please ask any questions about this study that you don't understand. You can take as long as you want to decide.

Authorization

You are making a decision whether or not to participate in this study. Your signature indicates that you have read and understood the information provided above, have had all your questions answered and decided to allow to participate.

Name of the Participant (please print)

_____

Date_____

_____ _____

Signature of the participant (agreement to participate in the study)

_____

Signature of the participant (agreement for the interview to be audio-recorded)

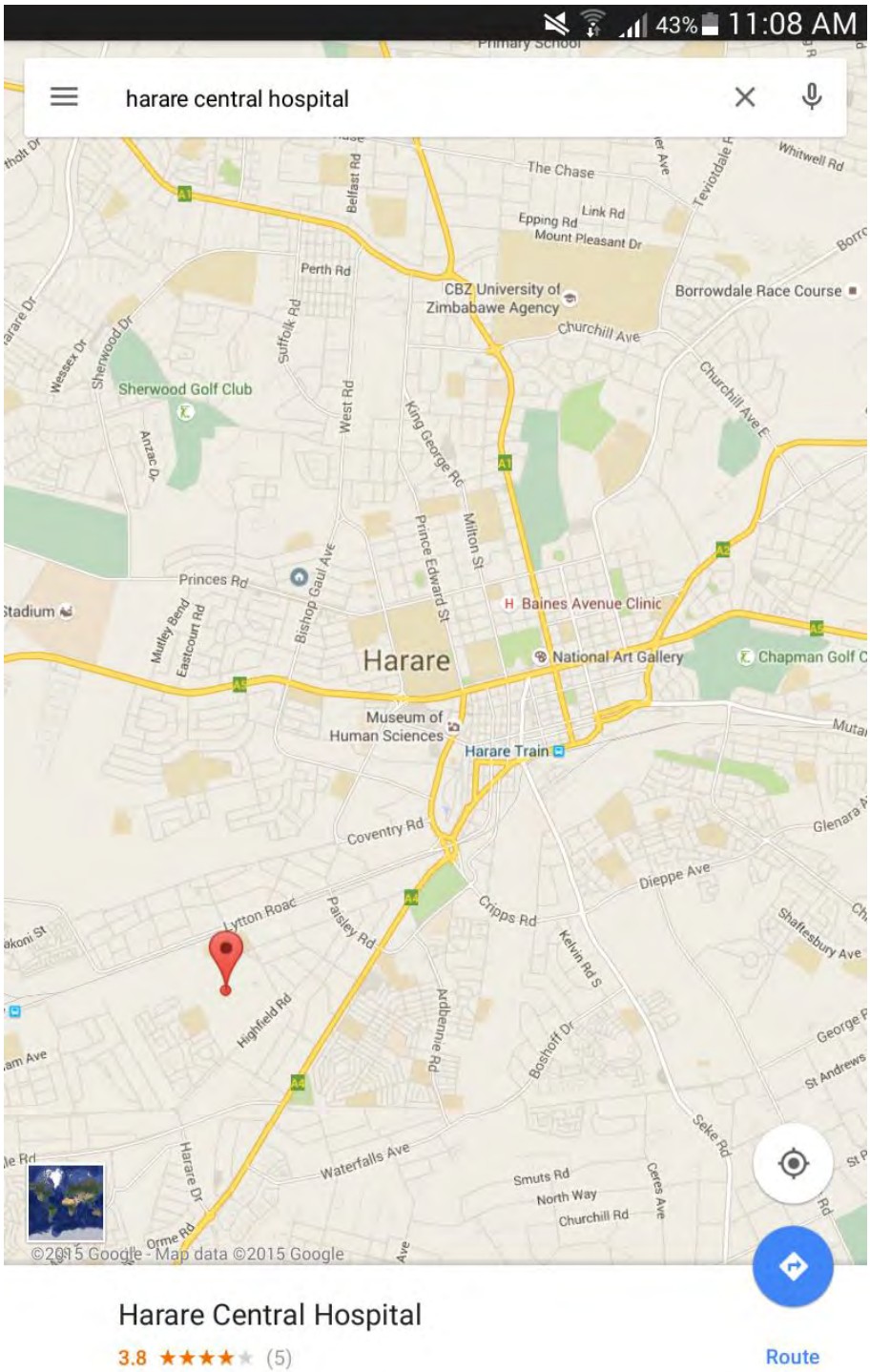
_____

Signature of Research staff

YOU WILL BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP

If you have any questions concerning this study or consent form beyond those answered by investigator, including questions about the research, your rights as a research participant or research related injuries, or if you feel that you have been treated unfairly and would like to talk to someone other than a member of the research team, please feel free to contact the Medical Research Council of Zimbabwe on telephone: 04-791792 or 04-791193 and Head of Paediatric Department, Dr. Louisa Chikara on telephone : 04 666519

APPENDIX V: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Prince Edward St
Princes Rd
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Ceres Ave
Seke Rd
Harare Dr
Orme Rd
©2015 Google - Map data ©2015 Google
Harare Central Hospital
3.8 ★★★★☆ (5)
Route

APPENDIXVI:

PRISMA 2009 Flow Diagram